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Associations Among End-Of-Life Discussions, Healthcare Utilization And Costs, And Race/ethnicity In Persons With Serious Illness

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Abstract

Acute care near end-of-life (EOL) is associated with lower quality of life and higher EOL costs, which are associated with worse quality death. Goals-of-care (GOC) discussions are associated with lower costs. Racial/ethnic minorities are less likely to have these discussions. It is unknown how costs and healthcare utilization differ by race/ethnicity following inpatient GOC discussion or how risk factor profiles are associated with discussion timing. Primary aims included: (1) Exploring associations among EOL discussions, costs, and proxies for costs (healthcare utilization, place of death) in persons with advanced cancer near EOL (Chapter 2); (2) Assessing future acute care costs and healthcare utilization among Whites and African Americans with serious illness who either did or did not have inpatient palliative care consultation to discuss GOC ("PCC") (n = 35,154; PCC: n= 1,197; non-PCC: 33,957) (Chapter 3); and (3) Examining risk factor profiles associated with timing of PCC before death (PCC 0-14 days before death, n = 612; PCC 15-60 days before death, n = 292; PCC more than 60 days before death, n = 237) among deceased persons who received PCC (Chapter 4). Secondary analysis included demographic, clinical, and financial data of patients 18+ admitted to a large, urban, academic medical center July 1, 2014 to October 31, 2016. Patients admitted for childbirth or rehabilitation, patients hospitalized at the end of the study, and for Chapter 3 patients who died during the admission they first received PCC were excluded. A systematic review (Chapter 2) found EOL discussions were associated with less acute and intensive care, greater hospice use, and lower EOL costs among advanced cancer patients. Propensity score matching (Chapter 3) showed PCC was associated with increased discharge to hospice among African American and White patients with PCC; and lower 30-day readmissions, fewer future days hospitalized, and lower future acute care costs (average $8,704 per patient) for Whites with PCC, but not African Americans with PCC. Multinomial logistic regression and classification and regression tree modeling (Chapter 4) showed a complex set of variable interactions were associated with PCC timing before death. Results imply need for investment in PCC across racial groups.

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ASSOCIATIONS AMONG END-OF-LIFE DISCUSSIONS, HEALTHCARE UTILIZATION AND COSTS, AND RACE/ETHNICITY IN PERSONS WITH SERIOUS ILLNESS

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ASSOCIATIONS AMONG END-OF-LIFE DISCUSSIONS, HEALTHCARE UTILIZATION AND COSTS, AND RACE/ETHNICITY IN PERSONS WITH SERIOUS ILLNESS

DEDICATION

This work is dedicated to my husband, Geoffrey, our children, Charlie and Gracie, my parents and sisters, and friends who supported me, encouraged me, and served as my village; to every person facing death and their families; and to God who makes all things possible.

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ABSTRACT

ASSOCIATIONS AMONG END-OF-LIFE DISCUSSIONS, HEALTHCARE UTILIZATION AND COSTS, AND RACE/ETHNICITY IN PERSONS WITH SERIOUS ILLNESS

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Acute care near end-of-life (EOL) is associated with lower quality of life and higher EOL costs, which are associated with worse quality death. Goals-of-care (GOC) discussions are associated with lower costs. Racial/ethnic minorities are less likely to have these discussions. It is unknown how costs and healthcare utilization differ by race/ethnicity following inpatient GOC discussion or how risk factor profiles are associated with discussion timing. Primary aims included: (1) Exploring associations among EOL discussions, costs, and proxies for costs (healthcare utilization, place of death) in persons with advanced cancer near EOL (Chapter 2); (2) Assessing future acute care costs and healthcare utilization among Whites and African Americans with serious illness who either did or did not have inpatient palliative care consultation to discuss GOC ("PCC") (n = 35,154; PCC: n= 1,197; non-PCC: 33,957) (Chapter 3); and (3) Examining risk factor profiles associated with timing of PCC before death (PCC 0-14 days before death, n = 612; PCC 15-60 days before death, n = 292; PCC more than 60 days before death, n = 237) among deceased persons who received PCC (Chapter 4). Secondary analysis included demographic, clinical, and financial data of patients 18+ admitted to a large, urban, academic medical center July 1, 2014 to October 31, 2016. Patients admitted for childbirth or rehabilitation, patients hospitalized at the end of the study, and for Chapter 3 patients who died during the admission they first received PCC were excluded. A systematic review (Chapter 2) found EOL discussions were associated with less acute and intensive care, greater hospice use, and lower EOL costs among advanced cancer patients. Propensity score matching (Chapter 3) showed PCC was associated with increased discharge to hospice among African American and White patients with PCC; and lower 30-day readmissions, fewer future days hospitalized, and lower future acute care

costs (average $8,704 per patient) for Whites with PCC, but not African Americans with PCC. Multinomial logistic regression and classification and regression tree modeling (Chapter 4) showed a complex set of variable interactions were associated with PCC timing before death. Results imply need for investment in PCC across racial groups.

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CHAPTER ONE: INTRODUCTION

Acute care near the end-of-life (EOL) is associated with lower quality of life[1] and 80% of medical spending in the last year of life.[2,3] This spending presents significant challenges to health systems tasked with managing costs while providing quality care, and to patients and families facing rising out-of-pocket costs. Patient-provider communication about goals-of-care (GOC) or EOL planning is associated with lower costs and lower rates of high-cost intensive care near EOL among persons with serious illness,[2,4-12] with timing of discussion potentially playing a critical role in utilization and quality outcomes.[12-16] Inpatient conversations occurring 30 days or more before death are associated with less aggressive and less costly forms of care than conversations occurring close to death,[12,15,16] but little is known about risk factors associated with the timing of these conversations,[17] or how the timing of these conversations is associated with acute care costs near EOL. Most studies of GOC/EOL communications and utilization or costs focus on patients with cancer and either do not break out outcomes by race/ethnicity or focus on predominantly White populations, resulting in a need for more research about these important conversations among racial/ethnic minority patients with serious illness.

Evidence suggests medical costs are significantly higher for racial/ethnic minorities in the last six months of life, compared to Whites, and that a significant portion of the higher costs are due to greater use of intensive procedures such as mechanical ventilation or intubation and care in the intensive care unit (ICU).[18] Unfortunately, racial/ethnic minorities are also less likely than Whites to have these important care planning conversations.[19] Little is known about the relationship between initial GOC/EOL discussion during hospitalization and acute care costs following discharge from a hospitalization involving these important conversations (hereafter called “future acute care costs”) by racial/ethnic group, or how race/ethnicity and the timing of these conversations are associated with acute care cost outcomes (see **Appendix A**).[20] To our knowledge, no published research has explored the relationship between inpatient palliative care consultation (PCC) to discuss GOC (hereafter called “PCC”) during an index admission (defined

as the hospital admission during which PCC first occurred in the study period) and future acute care costs by race/ethnicity, risk factor profiles associated with the timing of these conversations, or descriptions of EOL acute care costs following discharge from a hospitalization with PCC (hereafter called “EOL acute care costs”) based on PCC timing.

To fill these critical gaps, the specific aims of this dissertation are (see **Table 1.1**):

Aim 1: To explore associations among advance care planning, costs, and proxies for costs (healthcare utilization, place of death) in persons with advanced cancer near EOL using a systematic review of published literature (January 2012-January 2019) (Chapter 2).

Aim 2a: To assess differences in mean future acute care costs and healthcare utilization by race/ethnicity among African Americans with PCC, African Americans without PCC, Whites with PCC, and Whites without PCC (Chapter 3).

Hypothesis 2.1: Mean future acute care costs and utilization will be lower among persons who received PCC than persons who did not.

Hypothesis 2.2: African Americans who received PCC will have lower mean future acute care costs and utilization than African Americans who did not have PCC.

Hypothesis 2.3: Whites who received PCC will have lower mean future acute care costs and utilization than Whites who did not have PCC.

Aim 2b: To describe clinical and cost variables for Asian, Hispanic, and other racial/ethnic minorities in the dataset.

Aim 3a: To examine risk factor profiles for PCC patients who died during the study period based on the timing of consultation: PCC 0-14 days before death, PCC 15-60 days before death, and PCC more than 60 days before death (n = 1,141) (Chapter 4).

Hypothesis 3.1: African American race, younger age, Medicaid use, primary diagnosis of condition other than cancer, minor to moderate All-patient refined diagnosis related group (APR-DRG) Severity of Illness (physiologic decompensation of a patient, see **Appendix A**), minor to moderate APR-DRG Risk of Mortality (likelihood of patient dying, see **Appendix A**), ICU care during index admission, ICU care for more than six days during index admission, and Surgery source of referral to palliative care will be associated with PCC close to death (see **Appendix A**).

Aim 3b: To describe median EOL acute care costs, discharge to hospice from index admission, DNR documentation during index admission, and changes in GOC during index admission among deceased patients who received PCC 0-14 days before death, 15-60 days before death, and more than 60 days before death (Chapter 4).

This dissertation study fills critical gaps in the literature (1) by using the innovative methodology of stratified propensity score matching among multiple groups to quantifying cost savings across hospitalizations associated with PCC in different racial/ethnic populations,[7] (2) by using state-of-the-art classification tree modeling to examine risk factor profiles for the timing of PCC in inpatient settings where late conversations are most likely to occur,[17] and (3) by describing the EOL acute care costs of deceased patients based on PCC timing. The results of our study may be used to help systems manage costs when caring for persons with serious illness, including vulnerable patients near EOL. This research contributes to an emerging body of literature that explores factors related to racial/ethnic disparities in EOL care and costs.

Background and Significance

The High Cost of End-of-Life Care

High financial costs at EOL continue to burden patients, families, and the systems that care for them. Growing attention to the cost implications of treatment decisions for patients with serious illnesses necessitates research into aspects of care that may modify costs and financial burden, while aligning care with patient preferences.[1-3] In the United States, 10% of Medicare

patients account for almost 60% of Medicare annual spending,[4,5] with much of the spending occurring in the hospital and among persons at EOL.[6] According to a 2017 analysis of nine major countries, the United States spends an average of $80,000 on patients in the last year of life—more than any other country studied.[7] Acute care contributes to 80% of this medical spending in the last year of life.[8,9] This higher spending is influenced by Americans' high use of intensive care unit (ICU) and life-prolonging services (e.g., mechanical ventilation, resuscitation, feeding tubes).[8,9] For example, over 40% of adults 65+ who died of cancer in 2010 received ICU care in the last 180 days of life—a figure significantly higher than the 18% reported in other developed countries studied.[10] In some patient populations, aggressive EOL care has been shown to contribute to 43% higher costs than non-aggressive EOL care.[11] Despite patient preferences for less aggressive inpatient care near death and uncertainty about the value of intensive care at EOL, the average number of days patients spent in the ICU during the last six months of life is trending up in the United States.[12] Most importantly, this high utilization of aggressive treatments near EOL may not be consistent with patient preferences and values near EOL,[13,14] a critical problem.

Intensive, acute care near EOL is more costly than less intensive care, such as hospice,[8,15,16] with higher utilization of intensive care resulting in higher costs. For example, one study of deceased Americans found the cost of a terminal hospitalization involving care in an ICU cost an estimated $38,000 compared to $13,000 if ICU care was not involved.[17] High costs at EOL are also associated with perceptions of worse quality of death[8] and higher decision regret[18,19] among bereaved families of persons with serious illnesses, providing evidence that EOL costs have lasting non-financial effects as well. At the same time, health systems are challenged by the cost of inpatient EOL care, especially care in the ICU. With changing payment structures and financial penalties for readmissions, hospitals are under increasing pressure to manage costs during each hospitalization and across visits.[5] More research is needed to better

understand how types of care impact costs across hospitalizations in persons with serious illness near EOL.

Goals-of-Care Consultations May Reduce Costs and Intensity of Care

The purpose of EOL and care planning conversations is to help clarify patients' preferences about treatment and care and ensure the care patients receive is consistent with their expressed preferences.[20,21] Patient-provider conversations about goals and end-of-life include discussion about prognosis, treatment options, and aspects of both living and dying that clarify patients' goals, values, priorities, and preferences.[22] As intended, these discussions are associated with patients receiving EOL care consistent with expressed preferences.[23,24] These discussions are also associated with less aggressive treatment[5,8,19,25-32] and lower acute care costs among persons with serious illness.[5,8]

About seven in ten PCCs include these important GOC discussions.[5,33] By promoting clear communication about prognosis and patient preferences, PCC has been shown to provide care consistent with patient goals, improve satisfaction, reduce overall and ICU healthcare utilization, reduce use of laboratory testing and other ancillary services, and significantly lower hospital costs (9%-25% less) and pharmacy costs compared to usual care in hospital settings.[5,26-31,34-38] Among persons with advanced cancer, for example, these cost savings are even greater when a patient has other serious diseases/multiple comorbidities.[5,39] In some populations, PCC is even associated with a doubling of inpatient and outpatient hospice enrollment,[40] contributing to reductions in EOL costs. As May and colleagues conclude in their 2014 meta-review of palliative care's effect on costs, inpatient PCC programs provide better care to patients with serious illnesses and save hospitals money.[27] More research is needed to better understand how PCC involving GOC/EOL discussions influence healthcare costs and utilization across hospitalizations for persons with serious illness.[5]

The 2017 propensity-matched parent study of these data (n = 41,363) found statistically significant reductions in future acute care utilization and future acute care costs after patients received PCC.[5] Specifically, average future acute care costs were found to be more than $6,000 lower in patients who received PCC following initial hospitalization.[5] Patients who received PCC were less likely to incur "any future acute care cost" during a future hospitalization, had lower 30-day readmission rates, fewer average number of days in the hospital post-discharge, and fewer average number of days in the ICU post-discharge.[5]

One study that examined relationships between EOL discussions and EOL costs found direct costs in the last seven days of life to be 36% lower for patients who reported having EOL discussions about care preferences with their physicians compared to patients who did not have GOC/EOL conversations.[8] This 2009 study estimated costs using national per capita healthcare data tied to healthcare utilization, and featured data from 2004, which underscores the need for more current studies of healthcare utilization, actual costs, and EOL discussions among persons with serious illnesses. This study also analyzed outcomes of patients with cancer, highlighting the need for more research in persons with other serious illnesses, and similarly did not address the variable of race/ethnicity.

Finally, self-reported discussion with a physician about EOL care has also been found to be associated with lower direct costs of care in the last week of life, but authors focused exclusively on decedents with cancer, used estimated costs based on utilization and not actual cost data, and failed to report data on the association.[1] This study also underscores the need for actual costs outcomes research on a broader patient population and set of variables. Our study aims to address this need by providing actual direct cost data (see **Appendix A** for table of variables) for White and African American adults with serious illnesses.

Advance Care Planning

Advance care planning (ACP) is a process that includes discussing and documenting patient preferences about GOC for patients who may lose capacity or the ability to communicate preferences in the future.[41] It includes GOC conversations and may include discussion about EOL, and sometimes but not always occurs during PCC.[24,41] Existing studies define ACP discussions differently,[41] with some focused broadly on EOL care conversations[32,42-45] or GOC conversations,[46,47] while other studies focus more narrowly on hospice discussions[48] or a combination of advance directives, Physician Orders for Life-Sustaining Treatment (POLST) orders, or do-not-resuscitate (DNR) or do-not-intubate (DNI) orders[49-52] (See **Table 1.2** for definitions of terms). One study, for example, used a broad definition of ACP by studying PCC and any component of ACP—defined as any GOC discussion, advance directive, POLST order, or DNR/DNI order.[52] Just as little is known how GOC/EOL discussions relate to acute care utilization and costs near EOL, evidence about associations between ACP, these outcomes, and race/ethnicity is also limited. One recent study of case-control matched decedents found patients who had ACP had fewer inpatient admissions and inpatient days before death, and a $9,500 reduction in Medicare costs compared to patients who did not have ACP,[53] but gaps in cost analysis persist. In this dissertation, we systematically review the available literature to identify and address research gaps related to EOL communication and costs.

Timing of Goals-of-Care Conversations May Influence Costs and Intensity of Care

Although PCC benefits patients, the timing of these conversations also matters. If GOC/EOL discussions occur too close to death, patients and families may make pressured decisions leading to care that is not concordant with preferences.[20,32,54] In one study of advanced heart failure patients, PCC during terminal hospital admission was often either absent or very near death, with a median time of six days between PCC and death and only 24 hours between orders for comfort care and death.[55] One study found the median days between referral to PCC and death was 10 days for patients with chronic obstructive pulmonary disease, 12 days for

patients with heart failure, 14 days for patients with severe dementia, and 20 days for patients with cancer,[56] but it is unknown at what point, if at all, GOC were discussed. However, each additional day from hospital admission to GOC conversation was found to be associated with a 4% increased risk of aggressive interventions and in-hospital death, and 19% greater odds of ICU admission.[57] In many cases, patients may not receive the benefits of comfort care as early as they might have liked, possibly resulting in greater regret about care decisions.[19]

Evidence suggests the majority of early PCCs (90 or more days before patient death) occur in outpatient settings (84%) and the majority of late PCCs (less than 90 days before patient death) occur in inpatient hospital settings (82%),[7] making it important to understand risk factors associated with the timing of PCC in hospital settings where late conversations are more likely to occur.[58] Earlier PCC is associated with lower rates of inpatient care, ICU care, and emergency department utilization in the last month of life; and lower inpatient and outpatient costs in the last six months of life compared to persons receiving late palliative care less than 90 days before death.[58,59] Earlier PCC is also associated with greater family satisfaction with care, as well.[60] Family members of veterans whose first PCC occurred 91-180 days before death, for example, were more likely to rate their loved one's care as excellent compared to families of veterans whose PCC occurred 0-7 days before death (adjusted odds ratio = 1.37).[60] In this study, PCCs that took place more than one month before death were associated with higher ratings of emotional and spiritual support, and respectful care and communication.[60]

In the literature, "early" GOC discussions are defined inconsistently.[32,43,57,61,62] Some studies define "early" as occurring more than 30 days before patient death.[32,43] One study defined "early" as a GOC conversation occurring in the first month following diagnosis.[42] In contrast, another study generalized late timing to be when a patient had lost decisional capacity following hospital admission (requiring surrogate involvement).[62] In this case, the author implied late timing is actually too late. Despite differences in definition, it is important to understand outcomes associated with the timing of early and late inpatient GOC discussions.

Inpatient GOC discussions occurring 30 or more days before death are associated with less intensive healthcare utilization near EOL and greater quality of life than conversations occurring less than 30 days before death.[32,61] For example, Mack et al. found evidence that patients with advanced cancer who had EOL discussions more than 30 days before death were less likely to receive aggressive EOL care, acute care in the last 30 days of life, and chemotherapy in the last seven days of life; and were more likely to receive hospice care.[32] Ahuluwalia et al. found EOL care planning discussion in the first month following cancer diagnosis was associated with a lower likelihood of receiving acute care at EOL among veterans with advanced cancer.[42] Although evidence on GOC timing in cancer populations is growing, evidence is limited among patients with other serious illnesses. Our study aims to meet that need by assessing a broad population of persons with serious illness.

In addition, little is known about risk factors and risk factor profiles associated with the timing of GOC conversations in inpatient settings. To our knowledge, no known studies have assessed risk factors or the interaction of risk factors associated with time between PCC and death, or whether race/ethnicity is associated with the timing of inpatient PCC. Our study aims to address this gap by identifying risk factor profiles of patients based on the timing of consultation before death (PCC 0-14 days before death, PCC 15-60 days before death, and PCC more than 60 days before death). By exploring the relationship between the timing of PCC and EOL acute care costs, our study also aims to contribute to an emerging body of literature about the timing of inpatient communications and costs near EOL in patients with serious illness.

Racial/Ethnic Disparities in Goals-of-Care Discussions and End-of-Life Costs

Unfortunately, racial/ethnic minorities with serious illness in the United States are less likely than White persons with the same illnesses to have these important EOL discussions with healthcare providers and non-providers, such as family members.[63-68] As one recent study concluded, most racial and ethnic minorities with a serious illness have not talked with anyone

about their goals, values, or care preferences—a difference that may result in lower quality care.[63] This difference is unnecessary given that most racial minorities think doctors should discuss EOL care issues with patients [82% of African American adults, 83% of Hispanic adults, and 82% adults self-reporting as "Other" (compared to 87% of White adults)].[63]

Although research suggests health literacy, rather than race, predicts EOL preferences[69,70] and that communication-based interventions can influence these preferences,[69,71] African Americans are more likely than Whites to receive life-prolonging care in the last few days of life[72] and aggressive care at the end-of-life,[68,73,74] and are less likely to complete advance directives[68,72,75-77] or receive hospice care.[73,75] Compared to Whites, racial/ethnic minorities experience less ACP[63,78,79] and receive more intensive EOL care.[63,78,80-84]

Higher End-of-Life Costs among Racial/Ethnic Minorities

This higher use of intensive care contributes to greater costs for minorities near EOL. One large study (n = 158,780) of Medicare data found that in the last six months of life, medical costs were 32% higher for African Americans and 57% higher for Hispanics compared to Whites; and that about 40% of the higher costs for Non-Whites were due to greater use of intensive procedures (e.g., gastrostomies) and ICU hospitalization.[80] (Differences in age, sex, cause of death, morbidity burden, hospice use, and other variables accounted for the other differences in higher EOL costs for minority patients.[80]) African Americans and Hispanics were more likely to die in hospitals compared to Whites,[80] also contributing to differences in costs. Across races/ethnicities, expenditure dramatically increased in the last month of life, with Hispanics receiving the most costly care of any racial/ethnic group studied ($13,900 compared to Whites, whose expenditure averaged $8,900 in the last month of life).[80] These racial/ethnic disparities in ACP, EOL care, and EOL costs are concerning, and have prompted the National Academy of Medicine to call for more research on the subject.[24]

Innovation

The study is innovative in a number of ways. First, it fills gaps in the literature relevant to the care of persons with serious illnesses. Second, stratified propensity score matching is a robust, innovative method for exploring PCC, race/ethnicity, and cost outcomes. Similarly, classification tree modeling is an effective, novel way to identify associations between risk factor profiles (the interaction of risk factor variables) and the timing of PCC. Finally, study findings may further underscore the need for timely GOC and EOL discussions (hereafter called "EOL discussions") for patients with serious illness. Clinicians may use the results of our study to identify persons with risk factors for having EOL conversations close to death, then initiate those conversations earlier to help reduce disparities and enable EOL care consistent with preferences.

Goals-of-Care/End-of-Life Communications, Utilization, and Costs

Little is known about the relationship between EOL discussions and acute care utilization and costs across hospitalizations among racial/ethnic groups with serious illnesses.[61] The parent study of this dissertation research found future acute care costs to be significantly higher among persons with serious illnesses who did not receive PCC, compared to similar patients who had received PCC;[5] and that consultations involving GOC discussions may decrease future healthcare utilization and costs beyond initial hospitalization.[5] While most available research on EOL conversations and EOL costs focuses on healthcare utilization, not actual costs (see **Appendix A**),[61] or predominantly on the cancer population, no published research analyzes EOL communications, acute care utilization and costs, and race/ethnicity.[61] In fact, most available research on racial/ethnic disparities in EOL discussions focuses on advance directive completion,[63,85] documents that do not always include preferences for EOL care (see **Table 1.2** for description of terms) and alone may not facilitate care consistent with patient goals.[63,86] This dissertation research will explore race/ethnicity beyond the limited scope of advance directives by focusing on GOC discussions, which are more likely to result in EOL care concordant with patient values, goals, and wishes.[24]

Timing of Goals-of-Care and End-of-Life Discussions

Evidence about demographic, clinical, and financial risk factors associated with the timing of GOC discussions among adults with serious illness prior to death is very limited[61] (see **Table 1.1, Appendix A).** Although a small number of studies have assessed associations between healthcare utilization and the timing of EOL discussions,[32,42,43,57,62] they have generally focused on decedents with cancer and have not analyzed race/ethnicity or cost outcomes. It is unknown what variables are associated with the timing of consultations for EOL care planning. Because GOC and EOL discussions near death are associated with more aggressive interventions, ICU care, and death in the hospital,[32,42,43,57,61,62] it is important that clinicians be aware of factors associated with later EOL conversations to reduce any disparities in EOL communication and care. End-of-life acute care costs associated with the timing of such discussions are also unknown. And because high medical costs at EOL are associated with worse quality death among persons with serious illness,[8] it is ethically imperative that risk factor profiles associated with the timing of these discussions be explored.

Parent Study Dataset for Secondary Analyses

The parent study of this dissertation research (n = 41,363 patients) was conducted at a 776-bed, urban, academic medical center in the Northeast region.[5] The medical center is located in a racially, ethnically, and socioeconomically diverse city and service area. African Americans represent the largest racial or ethnic group (46%) in the medical center's service area population—Whites represent 36%, Asians 9%, and Hispanics 6%.[87] The majority (84%) of residents in the medical center's service area speak English at home, with translation services available for the 4% who speak Spanish at home and the 7% who speak an Asian language.[87] Less than half (49%) of residents age 25+ in the service area graduated from high school,[87] possibly influencing health literacy. In addition, a majority of families (53%) in the medical center's service area live in poverty, suggesting diversity in the dataset's socioeconomic representation.[87]

Finally, across the medical center's service area, one in four adults 60+ are in fair or poor health.[87]

The purpose of the parent study was to compare future acute care costs across hospitalizations following PCC between patients who had PCC (n = 1,853) and a propensity-matched cohort of patients who did not (n = 39,510). The study found PCC was associated with reductions in intensive care and other acute care utilization, and a mean cost-savings of over $6,000 per patient.[5]

Study data include admissions of patients age 18 and older who were admitted to the medical center between July 1, 2014 and October 31, 2016. To assess a population of patients with serious illness, patients were excluded if they had been admitted for childbirth or rehabilitation. Patients who died during index admission (the admission during which the first PCC occurred within the study period, see **Appendix A**) or whose discharge information was unknown (i.e., patients still hospitalized at the end of the study period) were excluded. The medical center's palliative care registry was then used to identify patients who received PCC specifically to discuss GOC, according to records indicating the reason for each PCC. Patients who exclusively received PCC for reasons other than GOC (e.g., pain management, spiritual distress, transition planning) were excluded to enable cleaner assessment of associations between GOC discussions, utilization, and costs. The medical center's cost accounting system (McKesson Health Solutions, King of Prussia, PA) was then used to track acute care utilization and direct costs (see **Appendix A)** forward after the index admission through the end of the study period ("future acute care costs").[5] According to the parent study, direct costs represent the best estimate of the actual cost of providing hospital services including nursing labor, other allied health professional labor, pharmaceuticals, supplies, procedures, and testing.[5] Utilization and costs incurred during the index admission were excluded.

The medical center's palliative care team, which primarily operates as a consultation service, includes physicians, advance practice nurses, registered nurses, social workers, a pharmacist, and a chaplain.[5] Managed by a nurse coordinator, the palliative care registry includes demographic and clinical information. The parent dataset ties these data to the utilization and financial data available from the cost accounting system.

Chapter Aims and Rationale

The aims of this three article for publication dissertation research are to: (Aim 1) Explore associations among ACP, costs, and proxies for costs (healthcare utilization, place of death) in persons with advanced cancer near EOL (Chapter 2); (Aim 2) (a) Assess future acute care costs and healthcare utilization among Whites and African Americans with serious illness who either do or do not have PCC (Chapter 3) and (b) describe PCC patients across racial/ethnic groups using cost and utilization variables, including discharge to hospice, DNR documentation, and changes in GOC; and (Aim 3) (a) Examine risk factor profiles associated with the timing of PCC before death (0-14 days before death, 15-60 days before death, more than 60 days before death) among deceased persons with serious illness, and (b) Describe median EOL acute care costs, discharge to hospice, DNR documentation, and changes in GOC based on PCC timing (Chapter 4).

Chapter 2

Aim. Chapter 2 presents a systematic review of published literature (January 2012-January 2019) describing associations between ACP/EOL discussions in persons with advanced cancer and financial costs and proxies for cost, such as healthcare utilization and place of death, near EOL. We chose to focus the review on persons with advanced cancer because half of patients with advanced cancer receive aggressive treatment within the last month of life.[32] Evidence suggests aggressive EOL care among persons with advanced cancer contributes to 43% higher costs than cancer care managed non-aggressively at EOL.[11] Given that cancer is one of the most expensive conditions to treat,[88] it made sense to focus on this important population. In addition, most

research on GOC/EOL discussions explores associations in the cancer population, limiting our opportunity to review studies of associations between ACP and costs in a broader population of persons with serious illness.

Rationale. The systematic review identified only three studies with cost outcomes, two of which were based on the same dataset. The review did not find any studies that assessed EOL communications and costs in the context of race/ethnicity. Finally, the review identified six studies related to the timing of ACP/GOC conversations, but none of the studies examined factors associated with the timing of GOC or EOL conversations—associations we will explore in this dissertation. Although consistent with the published literature, our Chapter 2 (systematic review) focuses on persons with advanced cancer, we will apply our findings to a broader population of persons with serious illnesses in Chapters 3 and 4.

Chapter 3

Aim. Chapter 3 describes a secondary analysis of a retrospective cohort study conducted at a large, urban, academic medical center in the Northeast region (n = 41,363). The goal is to understand if there is a difference in mean future acute care costs and healthcare utilization among the following subgroups of persons with serious illness: African Americans with PCC, African Americans without PCC, Whites with PCC, and Whites without PCC. Asian, Hispanic, and other racial/ethnic minorities in the dataset will also be described; as will DNR documentation during index admission and, for PCC patients, changes in GOC during index admission.

Rationale. Compared to Whites, racial/ethnic minorities experience less ACP/GOC planning,[63,78,79] receive more intensive EOL care,[63,78,80-84] and incur higher medical costs in the last six months of life.[80] High medical costs at EOL are associated with worse quality death.[8,89] Although PCC is associated with significantly lower hospital costs and utilization of acute care,[5,27,29,34-38] no published research explores associations between race/ethnicity and costs or utilization in the context of PCC. The parent study did not assess costs or utilization by

race/ethnicity, so it is unknown how race/ethnicity influences future acute care costs and utilization following PCC.

Chapter 4

Aim. Chapter 4 describes a secondary analysis of deceased patients who received PCC at a large, urban, academic medical center in the Northeast region (n = 1,141), supplemented by new data (Medicaid status and days between PCC and death) pulled from electronic medical records. The goals of this study are to: (a) examine risk factor profiles for PCC patients who died during the study period based on the timing of consultation: PCC 0-14 days before death, PCC 15-60 days before death, and PCC more than 60 days before death; and (b) describe median EOL acute care costs, discharge to hospice, DNR documentation, and changes in GOC by PCC timing.

Rationale. Goals-of-care conversations occurring more than 30 days before death are associated with less intensive healthcare utilization near EOL and greater quality of life[32,61] and use of hospice,[32] supporting the idea that time enables patients and families to make informed decisions possibly more consistent with preferences for less intensive care near EOL. Evidence suggests many patients who have GOC discussions with their providers have these conversations close to death,[32,42,43,62,90] typically in inpatient settings following a change in health resulting in hospitalization.[58] Racial/ethnic minorities are less likely to receive GOC discussions,[63,78,79] but among those who do have these conversations with providers it is unknown how close to death the conversations occur. In fact, despite the well-established relationship between GOC discussion timing and healthcare utilization and costs, little is known about patient and clinical risk factors associated with the timing of PCC conversations before death. Understanding risk factor profiles and EOL costs associated with the timing of discussions may contribute to developing clinical decision tools and encourage clinicians to have timely GOC discussions with patients.

Tables

Table 1.1 Key Variables and Analytic Plan for Main Aims

Aims	Independent variable(s)	Dependent variable (s)	Covariates	Analytical plan
Aim 1	End-of-life (EOL), goals-of-care (GOC), or advance care planning (ACP) discussion (e.g., advance directives, physician orders for life-sustaining treatment documentation)	Financial costs (dollars) or healthcare utilization (e.g., hospital days, ICU days, intensive or acute procedures, emergency department visits, use of hospice, et al.) or place of death near the end-of-life	Demographic and clinical variables in the literature (e.g., age, gender, primary diagnosis).	Systematic review of literature (January 2012 to January 2019)
Aim 2	1. Palliative care consultation for GOC ("PCC") (yes, no) 2. Self-reported race/ethnicity (White, African American)	1. Any future acute care cost following discharge from index admission (yes, no) 2. Future acute care costs following discharge from index admission (U.S. dollars) 3. Number of future hospital days following	1. Age 2. Gender 3. Medicaid status 4. Primary diagnosis 5. APR-DRG Severity of Illness at time of discharge 6. APR-DRG Risk of Mortality at time of discharge	Two stratified propensity score models (one for African Americans with and without PCC; one for Whites with and without PCC) were created using sociodemographic, clinical, and financial variables to account for potential inherent differences between the race-based

		discharge from index admission 4. Number of future ICU days following discharge from index admission 5. Any ICU care following discharge from index admission (yes, no) 6. 30-day readmissions following discharge from index admission (yes, no) 7. Patient discharge to hospice from index admission (yes, no).	7. ICU care during index admission (yes, no) 8. ICU care more than six days during index admission (yes, no) 9. Admitted to medical center within prior 30 days 10. Whether a patient was seen by Oncology during index admission 11. Direct cost of index admission (impact per $1000, for every increase of $1,000 in direct costs, the estimate shows the expected increase in getting PCC. …… The variable "Change in GOC" and documentation of DNR orders are also described. Asians, Hispanics, and other racial/ethnic minorities not matched by propensity scoring are described.	groups with and without PCC. Subsequent analysis focused on the two highest tiers of propensity scores for each model. Significance tests for continuous variables were analyzed using a pooled t test and percentage variables were analyzed using a Cochran–Mantel–Haenszel test. Statistical significance was taken at the 0.05 level.
Aim 3	1. Age 2. Gender 3. Race/ethnicity	<u>Timing of PCC before death</u> 1. "PCC close to death": PCC 0-14 days before death	1. Age 2. Gender 3. Race/ethnicity	To inform development of a classification and regression tree (CART) model, an adjusted multinomial logistic regression model was

	4. Medicaid status 5. Primary diagnosis 6. Source of referral to palliative care 7. APR-DRG Severity of Illness 8. APR-DRG Risk of Mortality 9. ICU care during index admission (yes, no) 10. ICU care more than six days during index admission (yes, no) 11. Whether a patient was visited by an Oncology team during the index admission (yes, no) 12. Prior acute care admission within 30 days of index admission.	2. "Moderately-timed PCC": PCC 15-60 days before death 3. "Early PCC": PCC more than 60 days before death	4. Medicaid status 5. Primary diagnosis 6. Source of referral to palliative care 7. APR-DRG Severity of Illness 8. APR-DRG Risk of Mortality 9. ICU during index admission (y/n) 10. ICU care more than six days during index admission (yes, no) 11. Whether a patient was visited by an Oncology team during the index admission (yes, no) 12. Prior acute care admission within 30 days of index admission. The following variables were used to describe the sample: 1. Change in GOC during PCC 2. Discharge to hospice from index admission or any future admission 3. EOL acute care costs (following discharge from hospitalization with PCC to point of death in health system).	created to identify variables associated with PCC timing before death. A CART model was then created to identify risk factor profiles (interaction of risk factors) of patients likely to receive early PCC, moderately-timed PCC, and PCC close to death.

Table 1.2 Definitions of End-of-Life Communication Terms (adapted from The National Academy of Medicine's *Dying in America* Report[1])

Term	Definition
Advance care planning	The process of discussing EOL care, clarifying values and goals, and documenting preferences through written documents and medical orders. The process can start at any time and occur over time, and becomes more focused as a patient's health declines. The discussions ideally include a patient's health care agent (the person who can make medical decisions for the patient should he or she lose decisional capacity) and the patient's primary clinician and care team members. The conversations are ideally recorded and updated. Finally, the conversations should allow for flexible decision making in light of the patient's current medical condition. [1]
Advance directive	Refers to different patient-oriented documents, including living wills and durable power of attorney for healthcare documents to name a healthcare agent, that patients can complete at any time, in any state of health. [1]
Living will	This advance directive document is a written or video-recorded statement about the types of medical care a person wants or does not want under specific conditions (e.g., terminal illness) should the person no longer be able to communicate their desires. [1]
Durable power of attorney for health care	This advance directive document allows a person to identify the name of their preferred healthcare agent, the person they want to make medical decisions for them should they lose the capacity to make decisions. [1]
Medical orders	Documents seriously ill patients create with their health professionals (usually a physician, but in some states a nurse practitioner or physician assistant), signed by the health professional as a doctor's order that other health professionals (including emergency personnel) are required to follow. [1]
Do-not-resuscitate (DNR)	Medical order to not resuscitate a patient. This order is written in a healthcare facility but does not cross care settings and may not be honored in the community. An "out-of-hospital DNR" is a do-not-resuscitate medical order that is intended to ensure a patient will not be resuscitated against his or her wishes when the patient is outside a healthcare facility setting (e.g., hospital or nursing home). [1]

Do-not-intubate (DNI)	Medical order to not intubate a patient. This order is written in a healthcare facility, but does not cross care settings and may not be honored in the community. [1]
Do-not-hospitalize	Medical order to not hospitalize a patient. This order is written in a healthcare facility, but does not cross care settings and may not be honored in the community. [1]
Physician Order for Life-Sustaining Treatment (POLST)	Medical orders signed by a physician that cross care settings and are honored in the community in an emergency. These orders span a range of topics that may emerge when caring for a person near EOL. Use of POLST differs by state, but is becoming more popular. [1]

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CHAPTER TWO: ASSOCIATIONS AMONG END-OF-LIFE DISCUSSIONS, HEALTHCARE UTILIZATION, AND COSTS IN PERSONS WITH ADVANCED CANCER: A SYSTEMATIC REVIEW

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Abstract

Background: Aggressive end-of-life (EOL) care is associated with lower quality of life and greater regret about treatment decisions. Higher EOL costs are also associated with lower quality EOL care. Advance care planning and goals-of-care conversations ("EOL discussions") may influence EOL health-care utilization and costs among persons with cancer.

Objective: To describe associations among EOL discussions, health-care utilization and place of death, and costs in persons with advanced cancer and explore variation in study measures.

Methods: A systematic review was conducted using PubMed, Embase, and CINAHL. Twenty quantitative studies published between January 2012 and January 2019 were included.

Results: End-of-life discussions are associated with lower health-care costs in the last 30 days of life (median US$1048 vs US$23482; $P < .001$); lower likelihood of acute care at EOL (odds ratio [(OR] ranging 0.43-0.69); lower likelihood of intensive care at EOL (ORs ranging 0.26-0.68); lower odds of chemotherapy near death (ORs 0.41, 0.57); lower odds of emergency department use and shorter length of hospital stay; greater use of hospice (ORs ranging 1.79 to 6.88); and greater likelihood of death outside the hospital. Earlier EOL discussions (30. days before death) are more strongly associated with less aggressive care outcomes than conversations occurring near death.

Conclusions: End-of-life discussions are associated with less aggressive, less costly EOL care. Clinicians should initiate these discussions with patients having cancer earlier to better align care. with preferences.

Background and Significance

Aggressive, life-sustaining end-of-life (EOL) care is associated with lower quality of life,[1] family perceptions of lower quality of care,[2,3] and greater regret about treatment decisions.[4] It is also more costly.[5-7] In one study, cancer patients who received aggressive EOL care incurred 43% higher costs than patients who received non-aggressive care.[8] High costs near EOL, which are a proxy for more acute care, are associated with worse quality of death[6] and may contribute to patients' financial toxicity, the financial burden and stress caused by cancer that is associated with myriad negative clinical and quality outcomes.[9-13] High costs also create hardship for families, one-third of whom report spending all or most of their savings on costs related to their loved one's terminal cancer care,[14] and for health systems tasked with managing costs while providing high-quality care.[15] Most importantly, costly aggressive care may not always reflect patient preferences.[4] To better align care with preferences, the National Academy Medicine and American Society of Clinical Oncology recommend patients and providers have goals-of-care (GOC) conversations[16] and that palliative care, which typically involves such discussions,[15] be integrated into standard oncology care.[17] These conversations may include discussions about patient values, prognosis, treatment options, aspects of living and dying, or specific interventions a patient may want if certain future conditions occur—all of which may occur in advance care planning (ACP).[18] Interventions that include communication about ACP and care preferences have been found to improve concordance between care preferences and actual care delivered.[19]

Given that the costs of cancer care may vary by diagnosis, stage of disease, and treatment options;[20] and that cancer disproportionately burdens racial minorities, who are often diagnosed at later stages when treatment may be very expensive,[20,21] it is important to understand how care planning conversations are associated with healthcare utilization and costs among persons with advance-stage cancer, when utilization and costs may increase.[20] Evidence suggests patient-provider discussions about EOL preferences are associated with less aggressive treatment near death[6,22,23] and that interventions involving GOC discussions may

reduce costs.[24,25] Cancer is the second leading cause of mortality in the United States and globally,[26,27] and one of the most expensive diseases to treat,[28] in part due to rapid (often expensive) advances in cancer science that are adopted as standard of care. Although reviews of ACP and costs among older adults exist,[29,30] variables and patient populations vary, limiting conclusions and warranting separate analysis among patients with cancer. The purpose of this review is to explore associations among ACP/GOC/EOL discussions, hereafter called "EOL discussions," healthcare utilization, and costs among persons with advanced cancer (Stage III+) or persons who died of cancer. This review will also assess consistency and variation in how studies define EOL discussions and measure healthcare utilization outcomes.

Methods

Literature search strategy. Authors used PubMed, Embase, and CINAHL databases to find studies conducted in the United States published from January 1, 2012 to January 8, 2019 that explored relationships between EOL discussions and financial costs, healthcare utilization, or place of death in adults with advanced cancer (see **Table 1** for search terms). Because healthcare payment schemes differ by country, resulting in different costs and ways to measure costs, studies outside the United States were excluded. Qualitative studies, studies of children or adolescents, and studies presented at meetings or as abstracts were excluded. To enable comparability of costs and utilization near EOL, studies of patients with primarily early-stage cancer were excluded unless they focused on EOL care. The authors screened titles in search results and selected abstracts for review. Data extracted from each study were organized in a table of evidence summarizing key characteristics and study quality (**Table 2**). The review followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations.[31] Two authors independently rated the quality of evidence using the Oxford Centre for Evidence-based Medicine grading guide.[32]

Results

Literature search. Systematic searches resulted in 2,911 unduplicated articles. Twenty-three additional articles were identified through references and search engine recommendations (**Figure 1**). After identifying relevant titles in each database and importing those listings into EndNote software, 236 unduplicated abstracts were reviewed. Based on review criteria, 20 studies were included.

Description of studies. Included studies were conducted with populations predominantly composed of patients with Stage III or IV cancer, or patients who recently died from cancer. Cancer types included breast,[33] hematological,[34,35] gynecological,[1,36,37] lung or GI,[38] and any type.[23,39-50] Sample sizes ranged from 84 to 2,752 participants, with a median of 226 participants per study. Two studies featured fewer than 100 participants.[36,40] All studies were conducted in the United States. Settings varied and included for-profit, not-for-profit, and government institutions. Some hospital-based studies incorporated data from outpatient care. The studies' comparator was an EOL discussion, defined as any conversation about EOL goals or treatment preferences with a healthcare provider or trained facilitator, documented in medical records or self-reported by patients or surrogates, or described as ACP, which sometimes includes advance directives (AD), physician orders for life-sustaining treatment (POLST), or do-not-resuscitate (DNR) or do-not-intubate (DNI) orders that suggest discussion about preferences. Because ADs, POLSTs, and DNR documentation may be associated with preference for treatment limitations,[41,51] results of studies that exclusively or predominantly assessed ADs, POLSTs, or DNR were differentiated. Three studies examined EOL costs using either EOL discussion or a proxy such as AD as comparator.[41,42,50] No studies examined the impact of out-of-pocket costs on patients. Eighteen studies assessed relationships between EOL discussions and healthcare utilization near death[1,23,33,35-38,40,43-50,52] and six studies assessed place of death.[1,33-35,37,44] In addition, six studies incorporated elements of time in their assessment of EOL discussions, generally referring to these discussions as early (31+ days before death) or late

(within 30 days of death), with later conversations typically occurring in inpatient settings.[1,23,39,47,49]

Quality of Studies. To assess study quality, two authors (L.T.S. and K.L.C.) independently used the Oxford Centre for Evidence-based Medicine Levels of Evidence grading guide.[32] Independent ratings were then compared. Disagreements on ratings (10% of studies) were resolved by further analyzing study methodology. One study was a retrospective analysis of a randomized clinical trial (RCT);[50] one study was non-randomized, intervention-based;[45] and 18 studies were observational.[1,23,33,35-38,40-44,46-49,52,53] Strengths of the studies included clearly-stated objectives and inclusion criteria, sample sizes adequate for meeting objectives, and well-defined outcomes and variables (**Table 2**). Study limitations included prevalence of retrospective cohort design; variation among independent variable measurement, with some studies assessing EOL discussions based on self-report and others based on medical chart review; diversity in outcomes measured; and small sample size for two studies,[36,40] limiting power and analysis (**Table 2**). Six studies received lower ratings because they did not account for confounders.[1,37,40,44,47,49]

Summary of Findings.

EOL discussion associated with lower EOL costs. Only three studies (two from the same dataset) measured costs,[41,42,50] but one of these studies was a high-quality RCT.[50] In their RCT, Patel and colleagues found patients with advanced cancer who received a six-month program to discuss and document EOL preferences with a trained lay health worker, and who later died (n=120), had lower total healthcare costs within 30 days of death (median [interquartile range], $1,048 [$331-$8,522] vs. $23,482 [$9,708-$55,648]; $p < .001$) than patients in the control group who died.[50] Fifteen months after randomization, total healthcare costs among the entire study population were lower in the intervention group, but the difference was not statistically significant (median [interquartile range], $86,025 [$63,255-$133,256] vs. $111,958 [$75,803-$171,025]; $p = .08$).[50]

The two studies by Garrido and colleagues[41,42] are limited in their applicability due to how authors defined and used EOL communications as variables. In their 2015 study, the authors assessed costs in the last week of life in terms of preferences for heroic treatment or no heroic treatment, as documented in ADs.[41] As expected, costs were lower among patients who reported a preference for no heroic measures at EOL (adjusted mean incremental effect = - $3,082, p = 0.03) compared to patients who preferred heroic measures.[41] Because AD completion was associated with a difference in EOL care preferences, the authors' results may be biased toward lower costs, limiting comparison to the RCT by Patel and colleagues. The other study by Garrido and colleagues claimed a self-reported EOL discussion with a doctor about EOL care preferences was significantly associated with costs in the last week of life (p = 0.001), but failed to provide cost data, limiting comparison.[42]

EOL discussion associated with less acute care near EOL. Despite variations in discussion comparators, we found each study in the review identified some, if not many, significant associations between EOL discussion and either lower costs near EOL,[41,42,50] lower utilization of high cost care such as acute or intensive care,[1,36-40,43,46,47,50] or reduced use or duration of hospital services.[1,36,38,45,47,49,50] Studies of EOL or GOC discussions not involving ADs or POLST found associations between these discussions and a lower likelihood of having acute care in the last 30 days of life [Odds Ratios (OR) ranging 0.43 to 0.69)[23,39,45,50] and a lower likelihood of receiving ICU care in the last 30 days of life (ORs 0.26 and 0.68),[45,46] with insignificant results suggesting trends toward lower utilization. Patients who complete ADs may be more likely to prefer less intensive EOL care,[41] but Cappell and colleagues (n=422) found similar odds: patients with an AD were similarly less likely to receive ICU care within 30 days of death (25% vs. 40%, OR 0.49, p = 0.001) than patients without ADs.[35]

Studies did not consistently measure readmission rates, emergency department visits, or length of stay, although those that did often found associations with reduced rates.[36,45,47,50] For example, Rocque and colleagues (n = 2,752) found patients who started or completed an ACP

discussion about care goals and preferences with a lay facilitator trained in the Respecting Choices method had lower hospitalization rates within 30 days of death (46% vs. 56%, p = 0.02) and that patients with ACP discussions had lower Emergency Department (ED) visit rates within 14 days of death (33% vs. 42%, p = 0.04).[45] In their RCT, Patel and colleagues found patients who received a structured ACP program involving GOC or care preference discussion before death were also less likely to visit the ED (5% vs. 45%, p < 0.001) or be hospitalized (5% vs. 43%, p < 0.001) in the last 30 days of life compared to the control group (n = 120 total deceased patients), and had fewer mean ED visits (p < 0.001) and fewer mean admissions (p < 0.001) in the last 30 days of life.[50] Hoerger and colleagues (n = 125 deceased patients) similarly found that palliative care visits to discuss treatment decisions were associated with a lower odds of hospitalization within the last 60 days of life (OR 0.62, p = .005).[38] In total, four studies found evidence of reduced hospital length of stay (LOS), as well.[36,47,49,50]

The six studies that assessed place of death found associations between EOL discussion and death outside a hospital, but generally used mixed definitions of ACP as the comparator.[1,33-35,37,44] Eckhert and colleagues (n = 163), who broadly defined an EOL discussion as an outpatient GOC discussion, AD, POLST, or DNR/DNI more than 30 days before death, found patients with ACP were more likely to die in hospice than the ICU (p = 0.001) or in a non-ICU acute care setting (p = 0.004).[34] Conceptualizing EOL discussion to also include ACP, GOC, and discussion proxies such as POLSTs and ADs, Zakhour and colleagues (n = 136) found patients who had a discussion inpatient had much higher odds of dying in the hospital than patients who had a discussion outpatient (34% vs. 0%, OR 20.5, 95% CI, 1.19 to 352.6, p = 0.04), providing context to possible relationships between discussion location and place of death.[37] In this study, 70% of patients had a GOC discussion, suggesting the findings may compare to studies with GOC as a comparator.[37] Studies that assessed place of death among patients who had ADs or POLST found similar results. For example, Cappell and colleagues found patients with ADs were less likely to die in the ICU and more likely to die at home (p = 0.003).[35] Pedraza and colleagues (n =

2,159) found the odds of dying outside the hospital were more than two times greater for patients with POLSTs than patients with ADs (OR 2.3, $p < 0.001$).[54]

Of the 11 studies that assessed hospice use, nine studies found significant associations with EOL discussions (ORs ranging 1.79 to 6.88).[23,33,34,37,38,40,44,48] Findings were strongest among studies that defined discussions based on EOL, GOC, and treatment preference conversations.[23,33,38,40,48] Among patients who died during the RCT (n = 120), for example, Patel and colleagues found an GOC intervention was associated with higher rates of hospice use (48% vs. 77%, $p = 0.002$; OR 3.51, 95% CI 1.6-7.69, $p = 0.002$).[50] Mack and colleagues (n = 1,231) also found patients who had EOL discussions were much more likely to receive hospice care (OR 6.88, 95% CI 4.36-10.8, $p<0.001$),[23] as did Gramling and colleagues (n = 231), who found patients engaged in a length-of-life discussion were more likely to enroll in hospice by six-month follow-up (OR = 2.16; 95% CI 1.25–3.73).[48] The two studies that defined EOL discussions based on a mix of GOC, ADs, and POLST use also found significant results.[34,37] Zakhour and colleagues, for example, found patients who had a conversation involving GOC, AD, or POLST 31+ days before death were more likely to have higher rates of hospice ($p = 0.001$) and more days in hospice ($p < 0.001$).[37] Adding context to these findings, Pedraza and colleagues found patients with POLST were more likely than patients with ADs to enroll in hospice (OR 2.69, 95% CI 2.25 to 3.22, $p < 0.0001$).[44] Two other studies that measured hospice use did not find significant results.[39,45]

Associations between EOL discussion and chemotherapy use near EOL were mixed. For example, Mack and colleagues (n = 1,231) found patients who had EOL discussions were less likely to have chemotherapy in the last 14 days of life (OR 0.41, $p < 0.001$)[23] and Hoerger and colleagues (n = 171) found palliative care visits that addressed treatment decisions were associated with lower odds of a patient receiving new chemotherapy within 60 days of death (OR 0.57, 95% CI 0.35 to 0.90, $p =0.02$).[38] However, Ahluwalia and colleagues (n = 665), who defined EOL discussion as any documented care planning discussion in the first month following cancer

diagnosis among veterans, did not find an association between discussion and chemotherapy near death (OR: 0.79, p = 0.35).[39] With or without an EOL discussion, Garrido and colleagues found baseline chemotherapy (median 3.5 months before death) was significantly associated with higher costs of care in the last week of life.[42] Studies of AD or POLST use did not assess late chemotherapy as an outcome.[35,44]

Earlier EOL discussion associated with stronger outcomes. Finally, the six studies that explored associations between EOL communications and care-related outcomes in the context of time identified significant associations.[1,23,37,39,47,49] Of the studies that exclusively looked at EOL discussions not AD or POLST documentation, earlier conversations (defined as occurring 30-31 days or more before death, typically in inpatient settings) were found to be associated with lower likelihood of receiving any aggressive care in the last 30 days or life (ORs ranged 0.10 to 0.34),[1,23] lower likelihood of receiving acute care in the last 30 days of life (ORs ranged 0.03 to 0.67),[1,23,39] lower likelihood of ICU care in the last 30 days of life (ORs ranged 0.19 to 0.33),[1,23] and greater likelihood of enrollment in hospice care (OR 2.8, 95% CI 2.06 to 3.75, p< 0.001).[23]

Some studies did not find significant associations between the timing of EOL discussions and hospice care or did not measure hospice enrollment overall but did measure time between hospice enrollment and death. Lopez-Acevedo and colleagues, for example, found early EOL discussions were associated with significantly more days of hospice care before death (median length of enrollment 53 days vs. 11 days, p < 0.001) and a lower likelihood of late enrollment in hospice within three days of death (OR 0.16, p = 0.02).[1] Zakhour and colleagues, whose sample predominantly engaged in GOC discussions but also may have completed ADs or POLST, found patients who had late EOL discussions were eight times as likely to either enroll in hospice within three days of death or not enroll at all (OR 8.0, 95% CI 3.3-19.2, p < 0.0001) than those who had an early conversation.[37] Earlier conversations were also associated with a much greater likelihood of patients dying outside the hospital (OR 8.9, p = 0.0001) compared to late conversations.[1]

Variation in conceptualization of EOL discussions. We found wide variation in how studies defined EOL discussions. Most studies based EOL discussions on documentation in the medical record or patient/surrogate reports of an EOL conversation with a healthcare provider; and others defined ACP in terms of documentation of medical orders such as DNR/DNI, POLST, AD, or living will. Some studies conceptualized EOL communication as a mix of terms. Eckert and colleagues, for example, defined ACP as documentation of an outpatient GOC conversation, AD or POLST, and/or DNR/DNI code status.[34] Professional health providers led most discussions, though two studies featured professionally-trained lay healthcare workers, reflecting trends to train both lay workers and a growing body of primary palliative care providers.[45,50] The wide variation in how clinicians and researchers define EOL discussions makes comparison difficult.

Variation in healthcare utilization outcomes. We also found wide variation in EOL healthcare utilization outcomes measured. These measures serve as proxies for costs, but also represent variance in how clinicians conceptualize aggressive care and overuse of healthcare services near EOL. For example, Loggers and colleagues defined intensive EOL care as resuscitation and/or ventilation in the last week of life followed by death in the ICU or hospice,[43] whereas Ahluwalia and colleagues defined an intensive intervention as any of the following occurring in the last 30 days of life: an ICU admission, new hemodialysis, placement of a gastric tube, new mechanical ventilation, or death despite attempts at cardiopulmonary resuscitation (CPR).[39] Furthermore, Mack and colleagues measured ICU care in the last 30 days or life, but also grouped measures into a category called “aggressive care” that included any ICU care or acute care in the last 30 days of life, or chemotherapy in the last 14 days of life.[23] Similar variations in conceptualizing or grouping measures were common across studies, making clean comparisons difficult. These findings suggest a lack of standardization in what may represent unnecessary care near EOL.

Discussion

This systematic review evaluated the relationship between EOL discussions about care planning and EOL costs, healthcare utilization, and place of death in persons with advanced cancer. The 20 included studies provide evidence that an EOL discussion is associated with less costly and less aggressive or intensive forms of care near EOL, and greater use of hospice services; and that relationships are even stronger when conversations occur 30 days or more before death. Findings were similar for studies that assessed proxies for EOL discussion such as ADs, POLST, and DNR orders. The implications of these findings are significant.

First, it appears patient-provider EOL discussions influence patients' decisions to receive less aggressive, less costly care at EOL, possibly due to a patient's increased knowledge and understanding of their illness and care options. Because less aggressive, less costly EOL care is associated with numerous quality outcomes,[1-4,55] EOL discussions about care preferences may help improve the EOL experience for patients and families.[3] To improve the EOL experience, clinicians should routinely have these conversations with cancer patients—and in a timely matter, not just in the weeks or days before death. For patients with cancer who are hospitalized, it is critical that clinicians initiate these discussions early in the hospital stay.

Although none of the studies assessed EOL costs or healthcare utilization by race, some studies did find evidence that racial minorities were less likely than Whites to have these important EOL discussions with their healthcare providers,[23,40] a finding that is consistent with the literature.[56-58] For example, Mack and colleagues found that compared to White patients, African American patients (OR 0.37, 95% CI 0.19 to 0.73) and Hispanic patients (OR 0.29, 95% CI 0.12 to 0.73) were less likely to experience EOL discussions ($p = 0.005$).[23] Clinicians should initiate EOL discussions with all their patients, especially racial and ethnic minorities who may be less likely to have these conversations.

As part of EOL care planning, clinicians may also consider discussing patients' financial wellbeing and the estimated costs of treatment options—not to make clinical decisions based on costs, but to acknowledge the financial burden cancer care has on patients and families and support informed decision-making. A majority of cancer patients report some desire to discuss treatment-related out-of-pocket costs with their care team, but less than 20% of patients actually discuss costs with their doctors.[59] In the study by Apostol and colleagues, the need patients reported providers most poorly met in GOC conversations was the need for more economic and insurance information related to cancer,[40] further supporting the idea that such conversations matter. The high cost of cancer care is associated with decreased quality of life and increased risk of mortality and morbidity,[9-11] making it a clinical and ethical concern.

End-of-life discussions also influence hospital and payer costs. One recent study found palliative care consultations for GOC/EOL were associated with a decrease in future acute care utilization, reducing future costs by more than $6,000 per patient.[15] Although EOL discussions should never be used to deny necessary care, hospitals and payers may benefit from patients choosing less costly forms of care when consistent with patient goals. Finally, this review highlights the need for more research about EOL communication and costs, the timing of discussions, and racial/ethnic disparities across such measures. Standardization of outcome measurement and greater consistency in definition of outcomes is recommended.

Limitations

This review has several limitations. First, only one study tested causal relationships through an RCT.[50] This study was also the only study to assess associations among EOL discussions for GOC and costs;[50] the other two cost studies compared AD utilization or did not adequately provide cost data.[41,42] Third, studies did not account for the same utilization variables, consistently define the variables, or collect data on variables the same way. Studies that used self-report to measure EOL conversations could not account for recall bias, while studies using

medical records could not account for undocumented conversations. Fourth, variation in healthcare utilization variables limits study comparison. Finally, studies captured results in different cancer populations and healthcare systems that have varying levels of efficiency, rates of intensive care at EOL, training in EOL communications, and resources.[39] These differences may limit generalizability of results. Despite these limitations, this review provides clinical insights that may help improve EOL care for persons with cancer and justify investment in EOL communication interventions.

Ethical Considerations

This review provides preliminary evidence that EOL discussions may reduce costs and utilization of aggressive EOL care. Reducing costs should not be a driving reason for engaging patients in EOL discussions.[60] Instead, clinicians and payers should consider EOL discussions an intervention that uniquely increases patient autonomy, improves quality of care and quality of death, and saves resources at the same time.[25] When communication is improved, better quality results and lower costs tend to follow, mutually benefitting patients and systems and further strengthening the case for EOL discussions.

Conclusions

End-of-life discussions are associated with lower EOL costs, less acute and aggressive care, less time spent hospitalized, greater use of hospice, and greater odds of dying outside the hospital—all outcomes associated with greater quality of life and quality of care. Separately, ADs and POLST documentation are similarly associated with reductions in intensive care at EOL. Earlier discussions about care goals give patients with advanced cancer more time to make informed decisions and result in higher quality EOL care that happens to be less costly. Clinicians should initiate EOL discussions with patients earlier to support patient-centered care and enable informed decision-making. More standardized research is needed to better understand relationships between these important discussions, healthcare utilization, and costs.

Illustrations and Tables

Figure 2.1 PRISMA flow diagram showing systematic review screening and inclusion process, adapted from Moher and colleagues [1]

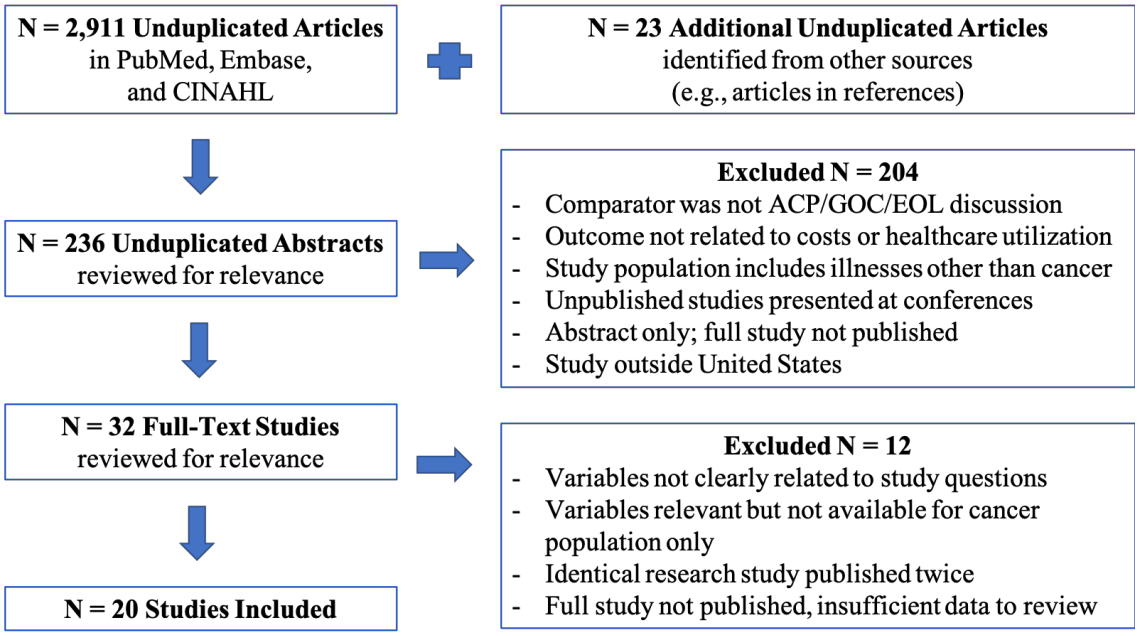

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Table 2.1 Systematic Review search strategy in PubMed, Embase, and CINAHL

Cancer terms	"Neoplasms"[mesh] OR cancer OR oncolog*
EOL terms	"end of life" OR end-of-life OR "terminal care"[mesh] OR end-stage OR advanced OR "stage III" OR "stage iv" OR terminal*
Communication terms	communicat* OR discuss* OR conversation* OR "advanc* care plan*" OR "advanc* directive*" OR "goals of care" OR polst OR "physician order for life sustaining treatment"
Financial terms	financ* OR "loss of income" OR "productivity loss" OR "economic burden*" OR "aggressive treatment" OR "aggressive care" OR "intensive care" OR ICU* OR "length of stay" OR "emergency room*" OR "emergency department" OR readmission* OR re-admission* OR readmi* OR hospice* OR cost* OR debt* OR bankrupt* OR "out of pocket" OR out-of-pocket OR "Cost of Illness"[Mesh] OR "personal cost*" OR "financial toxicity" OR expense* OR "financial burden"
Excluded terms	pediatric* OR paediatric* OR child* OR infan* OR neonat* OR newborn* OR adolescen* OR Britain OR Japan OR Uganda OR Korea OR Italy OR Ireland OR Australia[MeSH Terms]
Publication dates	January 2012- January 9, 2019

Table 2.2 Table of Evidence for Studies Included in Systematic Review[1]

Study	Study Design	Participant / Setting	Patient Attributes	Intervention/ Comparator	EOL Costs / Treatment Components Measured	Results	Study quality [2]
Ahluwalia et al., 2015 [1]	Retro-spective cohort study	665 veterans with stage IV colorectal, lung, or pancreatic cancer.	97.1% male, 74.7% white, mean age 66.4 years at time of diagnosis. 46.8% had care planning discussion within the first month of diagnosis.	Documentation of a care planning discussion in the first month following diagnosis compared to no documentation of discussion.	- Intensity of EOL care defined as acute care at EOL	Lower likelihood to receive acute care at EOL (OR: 0.67l; p = 0.025), but not associated with less intensive interventions (OR: 0.74, p = 0.28), late chemotherapy (OR: 0.79, p = 0.35), or hospice use (OR: 0.75, p = 0.09).	2b
Apostol et al., 2015 [2]	Pilot cohort study	86 hospitalized cancer patients at risk for	GOC meeting vs. no GOC:	Patients with GOC meeting (reported by physician as having occurred	- Receipt of critical care - Readmission to hospital within 30 days	Less likely to receive critical care (use of continuous veno-venous hemofiltration dialysis and/or ventilation) (0% vs. 22%, p =0.003); more likely to be	4

[1] EOL is end-of-life; ACP is advanced care planning; GOC is goals-of-care (conversation); AD is advance directive; POLST is physician order for life sustaining treatment; POST is physician order for scope of treatment; DNR is do not resuscitate; DNI is do not intubate; CPR is cardiopulmonary resuscitation; CI is confidence interval; SD is standard deviation.
[2] The quality of each study was assessed following the Oxford Centre for Evidence-based Medicine quality rating scheme.

		critical care in an academic medical center.	Mean age 54 vs. 60 (p = 0.03); white 56% vs. 78% (p = 0.05); male 67% vs. 50%; solid tumor 59% vs. 71%.	recently or during the study hospitalization) compared to patients without.	- DNR/DNI order - Discharge to hospice -Death during index hospitalization - Death within 30 days (including in hospital).	discharged to hospice (48% vs. 30%, p = 0.04). No statistical difference in readmissions, death during index hospitalization, or death within 30 days.	
Cappell et al., 2018[3]	Retro-spective cohort study	422 patients who died after allogeneic hematopoietic cell transplant (HCT) 2008-2015.	42% female, 56% White. Patients with ADs were older (*p* < .0001) and more likely to be White (*p* = .0007).	Documentation and timing of AD (pre-HCT, during HCT (day of HCT to day 30), or post-HCT)	-ICU days -Use of mechanical ventilation -Location of death	Patients without AD were more likely to have ICU admission after HCT (52% vs. 41%, *P* = .03), within 30 days of death (40% versus 25%, *P* = .001), and within 2 weeks preceding death (36% versus 21%, *P* = .001); more likely to undergo mechanical ventilation (37% versus 21%, *P* = .0007); more likely to die in hospital and less likely to die on hospice.	2b
Doll et al., 2013[4]	Retro-spective cohort study	84 gyn/onc patients near EOL discharged to hospice care after inpatient hospitaliza-tion	Hospice discussion group (HD, n = 15) vs. No-hospice discussion group (NHD, n = 69). Median age, 63 years.	Exposure to hospice discussion during the last outpatient clinical encounter prior to hospital admission.	- Length of hospital stay - Use of palliative care consultations during hospitalization	Decreased length of stay (3 days vs. 7 days, p = 0.008) and increased use of palliative care consultations during hospital stay (93.3% vs. 65.2%, p = 0.03). No significant difference in invasive procedures 4 weeks before hospitalization or chemotherapy 8 weeks before hospitalization.	2b

Eckhert et al., 2017 [5]	Single-center retrospect-ive cohort study	163 patients treated with HCT for a hematologic malignancy who died 2012-2015	53% male, 67% white; 34% multiple myeloma, 27% acute myeloid leukemia, 12% non-Hodgkin lymphoma.	Documentation of ACP: GOC outpatient, AD, POLST, and/or a code status of DNR/DNI > 30 days prior to death.	- Place of death: ICU, non-ICU acute care setting, hospice.	More likely to die in hospice than in ICU (p = 0.001) or non-ICU acute care setting (p = 0.004).	2b
Garrido et al., 2015 [6]	Prospect-ive cohort study with patient data and post-mortem caregiver interviews, 2002-2008.	336 deceased patients with advanced cancer and their caregivers	Mean age, 58.3 years; 54.5% male; 62.2% white, 19.6% black, 16.7% Hispanic.	ADs (based on preference for heroic or non-heroic EOL care)	Estimated costs of care received in the week before death based on average hospital expenditures, Medicare payment rates, and published estimates not actual costs.	ADs were associated with lower estimated costs in last week of life in adjusted models of patients who reported a preference for no heroic measures at EOL (adjusted mean incremental effect = - $3082, standard error = $1395, p = 0.03) compared to patients who wanted heroic measures.	2b
Garrido et al., 2016 [7]	Prospect-ive cohort study with post-mortem caregiver interviews, 2002-2008.	311 patients with advanced cancer who died 2002-2008.	Mean age, 59 years; 55% male; 61% white, 21% black, 17% nonwhite Hispanic	EOL discussion with a physician reported by patient during baseline interview	Costs of care estimated using reports of services (excluding chemotherapy) and place of death; based on average hospital expenditures, Medicare payment	EOL discussion significantly associated with lower costs in last week of life in unadjusted generalized linear models (p=0.001), however cost data was not reported for this variable.	2b

					rates, and published estimates.		
Gramling et al., 2018[8]	Multisite cohort study	231 patients with metastatic cancer	50% female; 13% African American, 8% Latino.	Discussion of length of life	-Hospice enrollment	Increased likelihood of enrollment in hospice by 6-month follow-up (OR = 2.16; 95% CI = 1.25–3.73).	2b
Hoerger et al., 2018[9]	Prospect-ive cohort study (secondary analysis of randomize d control trial data)	171 patients diagnosed within 8 weeks with advanced lung or GI cancer who received early palliative care	Mean age of sample was 65.44 years. 88.9% of patients were white.	Monthly palliative care consultation involving advance care planning.	-Healthcare utilization: chemotherapy, hospitalization, emergency department visits during the 60 days preceding death -Receipt of hospice care -Location of death	Visits focused on treatment decisions associated with lower odds of new chemotherapy (OR, 0.57; p = .02) and hospital admission (OR, 0.62; P = .005) 60 days before death. Higher proportion of visits focused on ACP associated with higher odds of hospice (OR, 1.79; P = .03).	2b
Loggers et al., 2013[10]	Multisite, prospect-ive, cohort study	292 self-reported Latino (n = 58) and White (n = 234) patients with Stage IV cancer	Hispanic vs. White populations: Mean age, 54.6 vs. 60.3 years (p = 0.01)	Self-reported EOL discussion with doctor about wishes for care if patient were dying, by ethnicity (White and Latino)	Intensive EOL care, defined as resuscitation and/or ventilation followed by death in an ICU.	No White or Hispanic patient who reported having EOL discussion at baseline received intensive EOL care. No difference in intensive EOL care among Latino and White patients with EOL discussion (p = 0.11).	2b

Lopez-Acevedo et al., 2013[11]	Retrospec-tive cohort study	220 women who died of advanced ovarian, fallopian tube, or primary peritoneal cancer diagnosed between 1999 and 2008, and treated by a gynecol-ogic oncologist.	Mean age, 61.2 years; 76% Caucasian, 21% African American; 87% ovarian cancer, 13% primary peritoneal cancer; 52% hospitalized in the last month; 62% had invasive procedures in the last 6 months of life, 35% had invasive procedures in the last month of life.	Documented EOL discussion with healthcare provider ≥ 30 days before death vs. < 30 days before death, defined as discussion with patient during which DNR status/ resuscitation, comfort care (i.e., transition from extending life to focusing on improving EOL symptoms and experience), or hospice care was mentioned.	Chemotherapy in the last 14 days of life, >1 hospitalization in the last 30 days of life, >1 ER visit in the last 30 days of life, ICU admission in the last 30 days of life, dying in an acute care setting, admission to hospice ≤ 3 days	EOL discussion ≥ 30 days before death associated with lower incidence of: chemotherapy in last 14 days of life ($p = 0.003$); >1 hospitalization in last 30 days of life ($p <0.001$); ICU in last 30 days of life (3% vs. 16%, $p = 0.005$); dying in acute care setting ($p = 0.01$); hospice initiated ≤ 3 days before death ($p = 0.02$), or any EOL quality measure (listed here) ($p <0.001$); lower likelihood of hospitalization in last month of life ($p < 0.001$) and in-hospital death ($p < 0.001$); fewer invasive procedures in last month of life ($p < 0.001$); and longer hospice enrollment (53 vs. 11 days, $p < 0.001$).	4
Mack et al., 2012[12]	Prospec-tive cohort study	1,231 patients with stage IV lung or colorectal cancer in the Cancer Care Outcomes	62% male; 76% non-Hispanic white, 12% non-Hispanic black, 5% Hispanic, 4% Asian; 61%	EOL discussions, identified via: a) Patient or surrogate report of a discussion with the physician about	- Chemotherapy in last 14 days of life - Acute care in last 30 days of life - ICU care in last 30 days of life - Aggressive. EOL care (any of above)	Patients with EOL discussions less likely to have chemotherapy in the last 14 days of life (OR 0.41, $p < 0.001$), acute care in the last 30 days of life (OR 0.43, $p < 0.001$), or any aggressive care in last 30 days of life (OR 0.40, $p < 0.001$); more likely to have hospice care (OR 6.88, p <	2b

		Research and Surveill-ance Consortium who died during the 15-month study period but survived at least 1 month.	married/living as married; 14% age 21-54, 25% age 55-64, 34% age 65-74, 27% 75+; 18% college degree or greater; 82% lung cancer, 18% colorectal cancer.	resuscitation or hospice care; b) Medical record documentation of a discussion about advance care planning or venue for dying.	- Hospice care - Hospice in the last 3 days of life, in last 7 days of life	0.001). No association found between EOL discussion and ICU care in last 30 days of life ($p = 0.55$). Patients with EOL discussion > 30 days before death less likely to receive aggressive EOL care ($p < 0.001$), acute care in last 30 days of life ($p < 0.001$), chemotherapy in last 14 days of life ($p =0.003$), and hospice 7 days before death ($p < 0.001$); more likely to have hospice ($p < 0.001$). ICU care in last 30 days of life insignificant ($p = 0.16$).	
Marcia et al., 2018[13]	Retrospec-tive cohort study	203 patients with stage IV cancer referred to acute care surgical service 2009-2016	Mean age 55. 51% female, 12% White, 43% Hispanic, 28% Black. 27% colon cancer.	Documentation and timing of AD	-Length of hospital stay -ICU length of stay	Patients who completed AD (including DNR status) post-admission had longer hospital lengths of stay ($P < 0.001$) and ICU lengths of stay ($P< 0.001$) compared to patients who continued full-code status throughout hospitalization and patients with a DNR on-admission.	4
O'Connor et al., 2015 [14]	Retrospec-tive cohort study	182 patients who died of metastatic breast cancer and eligible for hospice	Hospice vs. Nonhospice differences: ≤ high school education, 14% in hospice	Documentation of an advance directive discussion with oncology team	- Hospice utilization - Date of last chemotherapy - Medication use	Patients admitted to hospice more likely to have AD discussion documented ($p < 0.001$) and discussion of palliative care ($p<0.001$) than patients who died without hospice. Place of death was	2b

		1999 to 2010.	group vs. 31% in non-hospice group, p = 0.02.		- Place of death.	associated with hospice utilization (p < 0.001).	
Patel et al., 2018[15]	Randomiz-ed clinical trial (retrospec-tive analysis of randomize-ed quality improve-ment study)	213 veterans with Stage III or IV or recurrent cancer planning to receive care 2013 - 2015.	Mean age 69 years; 99% male. 78% non-Hispanic White, 5% Black, 3% Asian/Pacific Islander, 2% Hispanic.	Documentation of GOC/EOL preferences by oncology clinician within 6 months of randomization. Intervention: 6-month structured program where lay health worker assisted patients with ACP, including GOC, care preferences, choosing a surrogate decision maker, discussing AD, encouraging GOC discussion with providers.	-Health care use: chemotherapy, surgery, and radio-therapy use, VA and non-VA emergency department use, hospitalizations, inpatient and outpatient palliative care visits, and hospice service use -Total health care costs were measured a) 6 months prior to randomization, b) 6 months after randomization and c) 15 months after randomization	Patients in intervention group who died had fewer ED visits (*P* < .001) and fewer hospitalizations (*P* < .001), were more likely to receive hospice care (*P* = .002), and had lower health care costs within 30 days of death (median [interquartile range], $1048 [$331-$8522] vs $23 482 [$9708-$55 648]; P < .001) than patients in the control group who died. Patients in intervention group more likely to have used hospice within 6 and 15 months of randomization (*P* = .006; *P* = .009, respectively).	1b

Pedraza et al., 2017 [16]	Retrospec-tive cohort study	2,159 West Virginians with ADs and/or POLST who died of cancer 2011-2016.	Lung (28%), colorectal (9%), pancreatic (6%), breast (6%), prostate (3%), other (48%) cancers.	Use of POLST vs AD	Out-of-hospital death (OHD) and hospice admission	OHD 85.7% for patients with POLST, 72.0% for ADs ($p < .001$); hospice admission 49.9% for POLST, 27.0% for ADs ($p < .001$).	4
Rocque et al., 2017 [17]	Converg-ent, parallel mixed method design to evaluate implement-ation of navigator-led ACP across 12 cancer centers	2,752 deceased patients with cancer; 437 patients completed or were in the process of completing the lay Patient Care Connect Program (PCCP).	Group that completed or started the PCCP program: 56% male, 79.9% white, 51.7% high acuity.	Completion or involvement in program with ACP discussions vs. no involvement in program/ discussion.	- ER visit within 14 days and 30 days of death - ICU visit within 14 days and 30 days of death -Hospitalization within 14 days and 30 days of death	Patients who started or completed ACP discussion with a navigator had lower hospitalization rates within 30 days of death (46% vs. 56%, $p = 0.02$), but not within last 14 days of life (36% vs. 44%, $p = 0.09$). PCCP patients had lower ER rates within 14 days of death (33% vs. 42%, $p = 0.04$).	2b
Sharma et al., 2015 [18]	Multisite, prospect-ive cohort study with chart	353 terminally ill patients with metastatic	Mean age 58 years; 54% male; 64% white, 19% black, 16%	Self-reported recollection of EOL discussion with	- ICU care in the last week of life	Patients who had ICU care at EOL less likely to report EOL discussion with doctor (19% vs. 38%, $p = 0.02$) than patients who did not receive EOL ICU care.	2b

	review and interviews of caregivers to identify ICU stay in the last week of life.	cancer interviewed before death, and their caregivers, from six comprehensive cancer centers.	Hispanic; 23% lung cancer, 34% GI cancer, 12% breast cancer, 32% other cancer.	doctor (wishes about care patient would like to receive when dying); by gender.		Men with EOL discussion less likely to have ICU care at EOL than men without EOL discussion (odds ratio, 0.26; p = 0.04); no difference in EOL ICU for women based on EOL discussion (p = 0.4).	
Zakhour et al., 2015[19]	Retrospec-tive cohort study	136 patients who died of invasive gynecologic malignancies 2010-2012	Median age at death, 70 years; 79% White, 11% African American; 91% advanced stage (III/IV); 71% documented EOL discussion; 52% documented AD at death. 81% had EOL discussion in inpatient setting.	EOL discussion (GOC for EOL, hospice or palliative care, code status) or completion of AD or POLST (hereafter called "EOL discussion") >30 days before death	- Hospital admission last 30 days of life - ED visit last 30 days of life - ICU admission last 30 days of life - Death in hospital - Chemotherapy last 14 days of life - No hospice or ≤3 days hospice care - Non-compliant with ≥1 National Quality Forum (NQF)	Compared to patients who had late or no EOL discussion before death, patients with earlier discussions less likely to have inpatient admission (p = 0.001) in last 30 days of life; more likely to have hospice (p=0.001) and more days in hospice (p < 0.001), less likely to be non-compliant with ≥1 National Quality Forum (NQF) overutilization measures (12% vs. 38%, p = 0.005) Compared to patients with inpatient EOL discussion, patients with first discussion outpatient less likely to die in hospital (0% vs. 34%, p = 0.001) or have ICU care in last 30 days of life (p = 0.06).	4

					overutilization measures		
Zaros et al., 2013 [20]	Retrospec-tive cohort study	115 adult patients with advanced cancer who were documented to have decisional capacity upon admission and died in the hospital.	52% age > 65 years; 59% male; cancer type 37% lung, 30% bone marrow, 7% esophagus, 6% pancreatic, 5% liver, 5% colon, 10% other	Patients who participated in EOL discussion vs. patients who lost decisional capacity after admission and had surrogate participate in EOL discussion	Utilization during terminal admission: -Ventilation support - Chemotherapy - Artificial nutrition or hydration - Antibiotics - CPR - ICU treatment (admission or transfer) - Length of hospitalization	Patients who had EOL conversations themselves, compared to patients with surrogates, were less likely to receive ventilator support (23.2% vs. 56.5%, $p < 0.01$); artificial nutrition or hydration (25% vs. 45.7%, $p = 0.03$); chemotherapy (5.4% vs. 39.1%, $p < 0.01$); antibiotics (78.6% vs. 97.8%, $p < 0.01$); ICU treatment (23.2% vs. 56.5%, $p < 0.01$); had shorter length of hospitalization (mean 15.8 days vs. 10.3 days, $p = 0.03$).	4

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CHAPTER THREE: PALLIATIVE CARE CONSULTATION FOR GOALS-OF-CARE AND FUTURE HEALTHCARE UTILIZATION AND COSTS AMONG AFRICAN AMERICAN AND WHITE PATIENTS: A PROPENSITY-MATCHED STUDY

Abstract

Background: End-of-life (EOL) medical costs are higher for racial/ethnic minorities than Whites in the United States. Palliative care consultation to discuss goals-of-care (hereafter "PCC") is associated with lower use of intensive care and cost-savings. Little is known about how PCC-associated cost and utilization outcomes differ among African Americans and Whites.

Objective: To compare future acute care costs and healthcare utilization (30-day readmissions, future hospital days, future ICU admission and number of ICU days, and discharge to hospice) between African Americans who had inpatient PCC (n = 383) and a propensity-matched cohort of African Americans who did not (n = 10,777) and between Whites who had PCC (n = 814) and a propensity-matched cohort of Whites who did not (n = 23,180) in an academic medical center.

Methods: In this secondary analysis of a retrospective cohort study, stratified propensity score modeling was applied using sociodemographic, clinical, and financial variables to account for potential inherent differences between the race-based groups with and without PCC.

Results: There was no statistically significant difference between African Americans with or without PCC in accumulated mean future acute care costs ($11,651 vs. $15,050, P = 0.09), 30-day readmissions (P = 0.58), future hospital days (P = 0.34) future ICU admission (P = 0.25) or number ICU days (P = 0.30). However, there was a significant difference between Whites with PCC compared to Whites without PCC in in accumulated mean future acute care costs ($8,095 vs. $16,799, P < 0.001), 30-day readmissions (10.2% vs. 16.7%, P < 0.0001), future days spent hospitalized (3.7 vs. 6.3 days, P < 0.0001). PCC resulted in significantly greater discharge to hospice from index hospitalization for both African Americans and Whites (African Americans with PCC and without PCC, respectively, 36.5% vs. 2.4%, P < 0.0001; Whites with PCC and without PCC, respectively, 42.7% vs. 3.0%, P < 0.0001).

Conclusions: Our findings suggest PCC appears to decrease future acute care utilization and costs in White patients and, directionally but not significantly, in African Americans. Research is needed to explain why acute care utilization and cost disparities persist among African Americans despite PCC. These consultations are effective at dramatically increasing hospice use among African American and White patients.

Introduction

Despite growing evidence that patient-provider discussions about goals-of-care (GOC) and end-of-life issues (EOL) are associated with patients receiving EOL care concordant with preferences[1,2] and less aggressive treatment[3-13] perceived to be higher quality,[12,14-16] African Americans and other racial/ethnic minorities in the United States are less likely than Whites to have such conversations with their healthcare providers.[17-22] This disparity suggests an unmet need that may result in lower quality care.[17,23] Because race does not determine EOL preferences[24,25] and communication-based interventions can affect such preferences,[24,26] it is important to understand relationships between GOC discussions and the EOL care African Americans and other racial minorities receive.[27]

Communication disparities and differences in the effectiveness of EOL discussions[22] may help explain why minority patients are more likely than White patients to prefer and receive intensive EOL care[17,23,28-34] and less likely to receive hospice care.[35,36] These differences in healthcare utilization contribute to acute care spending disparities near EOL. One large study of Medicare data found that in the last six months of life, medical costs were 32% higher for African Americans and 57% higher for Hispanics compared to Whites; and that about 40% of the higher costs for racial/ethnic minorities was due to greater use of intensive procedures (e.g., mechanical ventilation, gastrostomies) and intensive care unit (ICU) hospitalization.[28] African Americans and Hispanics are also more likely to die in hospitals compared to Whites,[28] adding to differences in costs. Across races/ethnicities, expenditure is dramatically higher in the last month of life, with African Americans and Hispanics receiving the most aggressive and costly care.[28] These disparities in EOL costs persist across studies, even after controlling for individual and geographic factors.[37] Unfortunately, high medical costs at EOL are associated with worse quality death, underscoring the ethical need to understand EOL cost disparities among racial/ethnic groups and interventions, such as palliative care consultation, that mitigate those disparities.[12,38]

Palliative care consultations may involve discussion of GOC, pain and symptom management, psychosocial or spiritual distress, transition planning, or EOL issues. Inpatient palliative care consultations that specifically address GOC (hereafter called "PCC"), however, have been found to be associated with reductions in future acute care utilization, hospital readmissions, hospital days, and ICU use; and an average savings of over $6,000 in acute care costs following discharge from a hospitalization with PCC.[6] Some studies suggest cost reductions associated with GOC discussions, such as those occurring in PCC, are driven by lower utilization of inpatient care.[12,39,40] The benefit of PCC for patients and health systems appears to be mutual: patients who have these conversations seem to experience a higher quality dying experience more consistent with their preferences and health systems incur lower costs as a result.[12] In addition, early evidence of urban academic medical centers suggests race/ethnicity is not a factor in which patients receive PCC,[6,41-43] making it an intervention that may help overcome racial/ethnic disparities in EOL communication and care.

However, it is unknown how PCC is associated with acute care utilization and costs across racial groups, particularly among African Americans. The purpose of this secondary analysis is to compare future acute care costs and healthcare utilization (30-day readmissions, future hospital days, future ICU admission and number of ICU days, and discharge to hospice) between African Americans with serious illness who had PCC and a propensity-matched cohort of African Americans who did not, and between Whites with serious illness who had PCC and a propensity-matched cohort of Whites who did not. In addition, patients self-reporting as Hispanic, Asian, and "Other" racial/ethnic minorities will be described using demographic, cost, and utilization variables. The presence of a do-not-resuscitate (DNR) order during index admission and, among PCC patients, whether GOC changed during index admission will also be described.

Methods

Study Design

This secondary analysis included pre-existing clinical, administrative, and cost data from a retrospective cohort study that found PCC was associated with lower costs and lower use of acute care, but did not explore outcomes by race.[6] Supplementary Medicaid data was pulled from electronic medical records. Our sample included 35,154 self-identified African American and White patients 18 years or older admitted to a 776-bed urban, academic medical center in the Northeast region between July 1, 2014 and October 31, 2016 who were admitted for conditions other than childbirth or rehabilitation, were not hospitalized at the end of the study period, and did not die during index hospitalization (defined as the hospitalization during which the first PCC occurred). The hospital's palliative care registry, which includes demographic and clinical information such as the reason for consultation, was used to identify all patients who received a consultation with palliative care during the study period. Only consultations involving discussion of GOC were included (i.e., consultations to discuss pain management, but not GOC, were excluded). Our sample included 11,158 African Americans (PCC = 383; No PCC = 10,777) and 23,994 Whites (PCC = 814; No PCC = 23,180) (**Table 3.1**).

Future acute care utilization and accumulated direct costs (**Appendix A**) were tracked forward after discharge from the index hospital admission through the end of the study period using the medical center's cost accounting system (McKesson Health Solutions, King of Prussia, PA).[6] (Utilization and costs incurred during the index admission were not included in analysis, but are described in **Table 3.1**.) Direct costs represent the best estimate of the actual cost of providing hospital services including nursing labor, other allied health professional labor, pharmaceuticals, supplies, procedures, and testing (**Appendix A**).[6]

Setting

According to research by the medical center, the center serves a diverse area composed of 46% African Americans, 36% Whites, 9% Asians, and 6% Hispanics[44] and receives transfer

patients and referrals from surrounding suburban areas. Over half (53%) of families in the medical center's main service area live in poverty and one in four adults 60+ are in fair or poor health,[44] contributing to the population's diversity and need for quality care. The medical center's palliative care team is well-established and predominantly works as a consultation service.[6] Physicians, advance practice nurses, registered nurses, social workers, a pharmacist, and a chaplain make up the team. ICU teams request one-third of all consultations with palliative care.[6]

Procedures

The institutional review board of the University of Pennsylvania approved this secondary analysis study. The study followed University of Pennsylvania procedures for ensuring patient data privacy and security. To ensure Health Insurance Portability and Accountability Act (HIPAA) compliancy and participant privacy, all HIPAA-identifiers were removed prior to data transfer. Penn Medicine transferred de-identified data through Secure Share, an internet-based application for secure file exchange. Data was saved to a secure, encrypted folder on the University of Pennsylvania School of Nursing's network drive that exists behind firewall protection. Accessing the folder and the network drive requires two-step authentication. The network drive that contained the data is routinely monitored for system and security breaches. Only study investigators and university statisticians had access to the data.

Power Analysis

Based on the parent study's finding of $8,831 in future acute care costs among patients with PCC and $15,654 for patients without PCC, and variance of 10% (standard deviation unreported),[6] a sample of 771 Non-White patients who received PCC and a cohort of 15,780 Non-White patients who did not receive PCC achieves 91% power to detect a clinically meaningful difference of at least $2,000 in mean future acute care costs with a significance level (alpha) of 0.01 using a two-sided two-sample unequal variance t-test.[30,31,33] (The majority of Non-White patients in the dataset were African American.[6]) A $2,000 difference is a conservative

estimate given the parent study's finding of $6,000 cost-savings among the entire study population[6] and suggests adequate power in this study.

Measures

Independent variable. The primary independent variable is PCC as recorded in the palliative care registry according to patient self-identified racial group (African American, White). All hospital admissions during the study period were placed into one of four groups: (1) African Americans who had PCC, (2) African Americans who did not have PCC, (3) Whites who had PCC, and (4) Whites who did not have PCC (**Appendix A**). Although propensity score-matched analysis of other racial/ethnic groups is desirable, sample sizes for other racial and ethnic groups (Hispanics, Asians, American Indian/Alaskan Natives, Native Hawaiian/Pacific Islanders) were too small for independent group analysis. These patient populations are described using available clinical and cost variables (**Tables 7-10**, **Appendix A**).

Outcomes

Future Acute Care Costs. The primary outcome is future acute care costs, defined as accumulated mean acute care costs from all hospitalizations after the index hospitalization during the study period (**Appendix A**). We measured "future acute care costs" in two ways: (1) if a patient had any direct future acute care costs following discharge from index admission (yes, no) and (2) total direct future acute care costs a patient had during the study period following discharge from index admission, measured in U.S. dollars. Direct costs include hospital services such as physician and nursing labor, allied health professional labor, pharmaceuticals, supplies, procedures, testing, and emergency department (ED) visits that resulted in hospitalization. Direct costs provide the best estimate of actual costs, as they exclude indirect or fixed costs (i.e., overhead costs such as the cost of utilities) that cannot be reduced by avoiding future hospitalizations [6]. The medical center's cost accounting system, McKesson Health Solutions (King of Prussia, PA), provided acute care costs data based on charges coded during each hospital encounter throughout the study period. Healthcare costs outside the health system, such

as emergency room visits at local hospitals unaffiliated with the medical center, were not available and therefore not included, and have been identified as a limitation.

Future Healthcare Utilization. Secondary outcomes include (1) the number of future hospital days (in the health system) following discharge from the index hospital admission, (2) the number of future ICU days (in the health system) following discharge from the index hospital admission, (3) any ICU care following discharge from the index hospital admission (yes, no), (4) 30-day readmissions (in the health system) following discharge from index admission, and (5) patient discharge to hospice from index admission (yes, no) (**Appendix A**).

Covariates

Covariates include demographic variables such as age, gender, and Medicaid status (yes, no); acute care utilization 30 days before index hospitalization (yes, no); acute care costs accumulated during the index admission to represent acute care utilization (defined as the impact of $1,000; for every increase of $1000 in direct costs, the estimate shows the expected increase in getting a palliative care consult); and the following clinical variables (1) primary diagnosis at the time of index hospitalization discharge [based on diagnosis-related group (DRG)], (2) All Patient Refined (APR)-DRG Severity of Illness at the time of index admission discharge, (3) APR-DRG Risk of Mortality at the time of index admission discharge, (4) if the patient had any ICU care during the index admission (yes, no), (5) if the patient had ICU care greater than six days during the index admission (yes, no), and (6) whether the patient had Oncology services during the index admission (**Appendix A**).[6]

APR-DRG Severity of Illness and Risk of Mortality. APR-DRG Severity of Illness, which indicates the extent of physiologic decomposition or organ system loss of function in a patient, and APR-DRG Risk of Mortality, which indicates the likelihood a patient will die in the hospital, feature four subcategories (minor, moderate, major, extreme) that are assigned to a patient at discharge by an algorithm in the hospital's medical record software based on the diagnoses and

procedures coded for billing during the hospitalization.[6,45] Developed by 3M (St. Paul, MN) to enable hospitals to analyze patient risk and possible resource use, APR-DRG Severity of Illness and Risk of Mortality scores take into account a patient's comorbidities and the interaction of those illnesses, disease staging, and the kind of procedures and resources required by a patient during hospitalization.[46] High Severity of Illness and Risk of Mortality are characterized by multiple serious diseases and the interaction among those diseases. Severity of Illness appears to be associated with the risks of morbidity and mortality,[47] making it a proxy for considering comorbidity severity. Our study is unable to account for the number of comorbidities each patient has due to limitations in the dataset but uses Severity of Illness and Risk of Mortality to meaningfully express how sick a patient is at the time of index hospitalization.

Secondary Aims

Patients who self-identified as Asian, Hispanic, and "Other" race/ethnicity were not included in this propensity score-matched study. However, the parent dataset[6] included an additional 4,733 patients 18 years and older who self-reported to be a race/ethnicity other than African American or White who met our study criteria. These patients were also discharged from an inpatient hospitalization at the academic medical center and excluded patients who had been admitted for childbirth or rehabilitation, patients who died during index admission, and patients still hospitalized at the end of the study period.

For the secondary descriptive aim, which did not include propensity score matching to account for differences in patients with and without PCC, the sample included 961 Asians (PCC = 48; No PCC = 913); 851 Hispanics (PCC = 22; No PCC = 829); and 1,134 patients with "Other" race/ethnicity (PCC = 39; No PCC = 1,095). Healthcare utilization and costs of these patients are described in **Tables 3.7-3.10**. In addition, the presence of a DNR order during index admission (**Table 3.6**) and whether a patient changed GOC during PCC are described for African. Americans, Whites, Asians, Hispanics, and other racial/ethnic minority patients (**Table 3.1**, **Tables 3.7-3.10**).

Statistical Methods

Descriptive statistics were generated to characterize all variables and describe the sample (**Table 3.1**). Continuous variables were described using means and standard deviations following analysis with a Student's t test. Categorical variables were described as frequencies and percentages using a Chi-squared (χ^2) test. For the PCC groups, whether or not the patient changed GOC preferences is also included.

A systematic process to balance the four PCC-race groups (African Americans with and without PCC, Whites with and without PCC) was followed (**Tables 3.2 and 3.3**). We created two stratified propensity score matching models: one in the African American sample and then, separately, one in the White sample to account for possible inherent differences and nonrandom assignment of variables in the PCC and Non-PCC groups within each racial group. Before propensity scoring, patients in the PCC and Non-PCC groups for each race had different baseline characteristics (**Table 3.1**). For this reason, we employed a two-step matching process to make the PCC and Non-PCC groups similar for each race. First, we used logistic regression analysis with relevant variables available in the dataset to identify factors associated with the likelihood of an individual receiving PCC (**Table 3.2**). These variables included demographic data such as gender, age at time of index admission, and Medicaid status; and clinical and utilization data including primary diagnosis, APR-DRG risk of morality and severity of illness at the time of index admission discharge, ICU care during index admission (yes, no), ICU care greater than six days during index admission to indicate high acuity during the hospitalization, index admission acute care costs to represent acute care utilization; and prior inpatient hospitalizations in the health system during the 30 days before index admission.

The results from the final logistic model for African Americans and the results of the final logistic model for Whites are presented in **Table 3.2**. In both models, both the Akaike Information Criterion (AIC) and the Schwarz Criterion (SC) values became substantially lower when the covariates were included, showing much of the variation was explained by the predictors. As a

result, the model of African American PCC and Non-PCC patients had a C statistic of 0.907, indicating adequate model fit. The model of White PCC and Non-PCC patients had a C statistic of 0.901, also indicating adequate model fit.

Individual-level propensity scores were then created for each patient in the sample using output from the logistic regression models, by racial group. These individual propensity scores were then ranked and stratified into propensity tiers, from highest to lowest, to identify which patients were most likely to have received PCC (**Table 3.3**). Patients in the highest tiers were most likely to have received PCC. For each racial group's model, the patients in the PCC and Non-PCC groups were similar in terms of their propensity scores (**Table 3.3**), which enabled direct comparison of PCC patients to Non-PCC patients within tiers, within each racial group (**Tables 3.4 and 3.5**). To understand outcomes among patients with the highest likelihood of receiving PCC per racial group, subsequent analysis focused on the two highest tiers of propensity scores for each model. Lower propensity tiers were excluded because very few patients with a low propensity score actually received PCC. Significance tests for continuous variables were analyzed using a pooled t test and percentage variables were analyzed using a Cochran–Mantel–Haenszel test. Statistical significance was taken at the 0.05 level.

Missing Data

Although clinicians try to obtain and document complete data on every patient, missing clinical and administrative data is inevitable due to human error, oversight, or time constraints.[48] The parent study handled missing data by examining the underlying mechanism for missing data—missing completely at random (MCAR), nonignorable or not missing at random (NMAR)—prior to adjusting to minimize bias from missing data.[48-50] Most missing data was found to be MCAR (e.g., clinicians may have found data collection burdensome). For this reason, complete-case only analyses for data missing completely at random was used to analyze missingness. Although the number of patients with missing data was small (<5%) and missing data was considered MCAR, the parent study opted to exclude 0.4% of patients due to missing data.

Primary hypotheses were then tested on the remaining dataset. There was no missing data for our study, so additional analyses were not necessary.

Results

The sample for this study included 35,154 patients who were discharged from an inpatient hospitalization at an academic medical center in the Northeast region (**Table 3.1**). The sample included 1,197 patients who received PCC prior to discharge and 33,957 patients who did not. Specifically, the sample was composed of 11,160 African American patients (PCC = 383, Non-PCC = 10,777) and 23,994 White patients (PCC = 814, Non-PCC = 23,180).

At baseline, before propensity score matching, African Americans in the PCC group were significantly different from African Americans in the Non-PCC group (**Table 3.1**). Compared to African Americans who did not receive PCC, African Americans who received PCC were more likely to be older; less likely to have Medicaid; more likely to have cancer, a cardiovascular disorder or heart failure, a respiratory disorder, an infectious disease or sepsis and less likely to have an endocrine disorder, GI disorder, gynecologic or urologic disorder, neurologic disorder, or "other" condition; more likely to have major or severe severity of illness; more likely to have major or severe risk of mortality; more likely to have been hospitalized in the 30 days prior to index admission; more likely to have had ICU care during the index admission; more likely to have had ICU care for greater than six days during the index admission; more likely to have been seen by Oncology providers during the index admission. These differences are reflected in PCC patients' average utilization and costs during index admission. Compared to African Americans without PCC at baseline, African Americans with PCC had longer length of stay, more days in the ICU, and more than twice the average direct costs accrued during index admission, suggesting sicker African American patients received PCC.

At baseline, before propensity score matching, White patients in the PCC group were also significantly different from White patients in the Non-PCC group (**Table 3.1**). Compared to Whites who didn't receive PCC, Whites who received PCC were older; more likely to have

cancer, an infectious disease or sepsis, or a respiratory disorder and less likely to have a cardiovascular disorder or heart failure, endocrine disorder, GI disorder, gynecologic or urologic disorder, neurologic disorder, or "other" condition; more likely to have major or severe severity of illness; more likely to have major or severe risk of mortality; more likely to have been hospitalized in the 30 days prior to index hospitalization; more likely to have received ICU care during index admission; more likely to have received ICU care for more than six days during index admission; more likely to have been seen by Oncology providers during index admission; and more likely to have a DNR documented during the index admission. Like African Americans, these differences are reflected in PCC patients' average utilization and costs during index admission. Compared to Whites without PCC at baseline, Whites with PCC had longer length of stay, more days in the ICU, and twice the average direct costs accrued during index admission, also suggesting sicker White patients received PCC.

After the African American PCC and Non-PCC groups were propensity score matched on available variables (**Table 3.2**), the group of African Americans who received PCC and the group of African Americans who did not became similar (**Table 3.3**), such that the only difference between the groups was whether or not a patient had PCC. The groups of Whites who had PCC and Whites who did not have PCC also became similar after propensity score matching (**Table 3.3**). By matching variables within racial groups such that PCC is the only difference between groups within races, we were able to identify differences in outcomes associated with PCC.

Cost Outcomes

Any future acute care cost. Compared to African American patients who received PCC, African American patients who did not receive PCC were significantly more likely to incur "any future acute care cost" across the two highest propensity tiers when blended (31.9% vs. 37.7%, P = 0.047), but not when tiers were assessed separately (highest tier, 33.7% vs. 38%, P = 0.26; second highest tier, 29.5% vs. 37.3%, P = 0.08) (**Table 3.4**). White patients who received PCC were also significantly less likely than White patients who did not receive PCC to incur "any future

acute care cost" across the two highest propensity tiers when blended (25.9% vs. 35.5%, P < 0.0001) and when top tiers were assessed separately (highest propensity tier, 26.9% vs. 33.9%, P = 0.008; second highest propensity tier, 24.5% vs. 37.2%, P < 0.0001) (**Table 3.5**).

Total future acute care costs. Although average accumulated future acute care costs were lower across propensity tiers among African Americans with PCC compared to those without PCC (highest tier, $11,452 vs. $15,867, P = 0.055; second highest tier, $11,925 vs. $14,256, P = 0.53; blended top two tiers, $11,651 vs. $15,050, P = 0.09), the differences were not statistically significant (**Table 3.4**). Data support a trend toward an average difference in future acute care costs of $4,415 between PCC and Non-PCC African American groups in the highest propensity tier, but the difference was not statistically significant (P = 0.055). However, average future acute care costs were significantly lower among Whites who had PCC across tiers (highest tier, $8,302 vs. $14,995, P < 0.0001; second highest tier, $7,813 vs. $18,558, P < 0.001) and when the top two tiers were blended ($8,095 vs. $16,799, P < 0.001) (**Table 3.5**). In effect, PCC among Whites is associated with an average difference in future acute care costs of $6,693 (highest tier) to $10,745 (second highest tier) per person ($8,704 difference in blended top tiers). A large effect-size difference is represented among White patients with PCC.

Healthcare Utilization Outcomes

Increase in hospice utilization among African Americans and Whites. African American patients with PCC were more likely to be discharged to hospice from index admission than African Americans without PCC (highest tier, 30.3% vs. 2.6%, P <0.0001; second highest tier, 45% vs. 2.3%, P < 0.0001; blended top tiers, 36.5% vs. 2.4%, P < 0.0001) (**Table 3.4**). White patients with PCC were also more likely than White patients without PCC to be discharged to hospice from index admission (highest tier, 41.1% vs. 3.3%, P <0.0001; second highest tier, 44.8% vs. 2.8%, P < 0.0001; blended top tiers, 42.7% vs. 3.0%, P < 0.0001) (**Table 3.5**).

30-day readmissions. Significant differences among African Americans with and without PCC were not evident in 30-day readmission rates (highest tier, 15.7% vs. 16.3%, P = 0.84; second

highest tier, 17.8% vs. 14.6%, P = 0.31; blended top tiers, 16.6% vs. 15.4%, P = 0.58), but were evident among Whites with PCC compared to Whites without PCC (highest tier, 11.4% vs. 15.8%, P = 0.03; second highest tier, 8.6% vs. 17.6%, P = 0.0002; blended top two tiers, 10.2% vs. 16.7%, P < 0.0001).

Future days in hospital post-discharge. Significant differences in the number of future hospitalized days were not found among African Americans with and without PCC (highest tier, 5.8 vs. 6.7 days, P = 0.18; second highest tier, 5.5 vs. 6.0 days, P = 0.74; blended top two tiers, 5.5 vs. 6.4 days, P = 0.34), but were found among Whites with PCC compared to Whites without PCC (highest tier, 3.6 vs. 5.7 days, P = 0.04; second highest tier, 3.9 vs. 7.0 days, P = 0.0006; blended top two tiers, 3.7 vs. 6.3 days, P < 0.0001).

Future admission to ICU. African Americans with PCC were no less likely than African Americans without PCC to be admitted to the ICU following index hospital discharge (highest tier, 17.4% vs. 15.8%, P = 0.58; second highest tier, 15.5% vs. 12.6%, P = 0.34; blended top two tiers, 16.6% vs. 14.2%, P = 0.25). Results were similar for Whites, among whom there were no significant differences in future ICU admission by PCC or Non-PCC group (highest tier, 12% vs. 13.9%, P = 0.33; second highest tier, 13.2% vs. 14.9%, P = 0.46; blended top two tiers, 12.5% vs. 14.4%, P = 0.20).

Future days in ICU post-discharge. Significant differences in the number of future ICU days were also not found among African Americans with PCC compared to those without (highest tier, 1.3 vs. 1.2 days, P = 0.81; second highest tier, 1.3 vs. 0.80 days, P = 0.28; blended top two tiers, 1.3 vs. 0.99 days, P = 0.3). Among Whites with and without PCC, significant differences in the number of future ICU days were only evident in the highest propensity group (0.6 vs. 0.9 days, P = 0.042; second highest tier, 1.0 vs. 1.6, P = 0.85; blended top two tiers, 0.8 vs. 1.0 days, P = 0.15).

Results of Secondary Aims

Presence of a DNR order during index admission. **Table 3.6** describes differences in DNR documentation among the propensity-matched cohorts of African Americans and Whites with and without PCC. Although DNR documentation could not be assessed as an outcome because the timing of DNR documentation during index admission may have occurred before, during, or after PCC, associations with increased DNR documentation among PCC groups was also significant. Across tiers, African Americans with PCC were almost 9 times more likely to have a DNR than African Americans without PCC (blended top two tiers, 46% vs. 5%, $P < 0.0001$). Similarly, Whites with PCC were 8.5 times more likely to have a DNR than Whites without PCC across tiers (blended top two tiers, 54% vs. 6%, $P < 0.0001$) (**Table 3.6**).

Description of Asian patients with and without PCC. **Table 3.7** describes Asian patients who had PCC (n = 48) and Asian patients who did not have PCC (n = 961) prior to discharge from index admission. Propensity score matching was not used on these groups to make them similar, so data is best understood as descriptive. However, some differences among groups was still apparent. For example, Asians with PCC had significantly greater mean number of hospital days, ICU days, and direct acute care costs incurred during index hospital admission than Asians without PCC ($P < 0.0001$). Almost six out of ten Asian PCC patients (58%) changed their GOC, likely contributing to the significantly higher hospice use at time of index discharge among Asian PCC patients (33.3% vs. 0.8%, $P < 0.0001$) and DNR documentation (35.4% vs. 2.4%, $P < 0.0001$) compared to Asians without PCC.

Description of Hispanic patients with and without PCC. Propensity-score matching was also not applied to Hispanic patients in our sample. **Table 3.8** describes Hispanic patients who had PCC (n = 22) and Hispanic patients who did not have PCC (n = 829) prior to discharge from index admission. Hispanics with PCC also had greater mean number of hospital days and ICU days ($P < 0.0001$), and direct acute care costs ($P = 0.0005$) incurred during index hospital admission than Hispanics without PCC. Similar to Asians, about six out of ten Hispanic PCC

patients (59.1%) changed their goals-of-care during PCC. Hispanic PCC patients were also more likely to be discharged to hospice (31.8% vs. 0.4%, P <0.0001) and have a DNR documented during index admission (31.8% vs. 0.97%, P < 0.0001) compared to Hispanics without PCC.

Description of Other racial/ethnic minority patients. **Table 3.9** describes patients with "Other" race/ethnicity (self-reported as "Other" race/ethnicity, American Indian or Alaska Native, or Native Hawaiian or Pacific Islander) who had PCC (n = 39) and did not have PCC (n = 1,095). These patients were also not matched using propensity scoring. Like all other patients in the sample, other racial/ethnic minority PCC patients had index admissions with higher mean number of days hospitalized (P <0.0001), higher mean number of days spent in the ICU (P < 0.0001), and higher mean direct acute care costs (P = 0.0002), indicating the greater acuity among PCC patients. Almost seven out of ten other racial/ethnic minority PCC patients changed their goals-of-care during PCC. These PCC patients were also more likely to be discharged to hospice from index admission compared to Non-PCC patients (28.2% vs. 1.6%, P < 0.0001) and have a DNR (46.2% vs. 3.5%, P < 0.0001).

Descriptive comparison of PCC patients across racial/ethnic groups. **Table 3.10** explores differences among PCC patients across racial/ethnic groups. Again, these racial groups were not matched on available variables. Patients with "unknown" race/ethnicity include those who did not self-report their race/ethnicity. While there was no difference in mean index admission costs (P = 0.17), there was a statistically significant difference in median acute care costs accrued during the index admission (P = 0.04), with African American and Hispanic PCC patients spending the most, or most heavily using acute care services, consistent with other literature.[28] Asian PCC patients accumulated the lowest median costs during index admission (median $14,739; IQR $24,510), but one of the highest mean costs ($46,739, SD $81,216), suggesting very high utilization among some Asian patients. Future acute care costs appear to differ by race, with any future cost (P = 0.004), mean future acute care costs (P = 0.047), and median future acute care costs (P = 0.02) all showing statistically significant differences. Thirty-day readmission rates also

significantly varied by race (mean 13.3% yes, P = 0.006), with African American and Hispanic PCC patients demonstrating the highest readmission rates (18.3%, 18.2% respectively) and White and Unknown race/ethnicity PCC groups demonstrating the lowest rates (11.6%, 4.8% respectively). Significant differences were also observed in the number of future hospital days (sample mean 4.5 days, P = 0.005; sample median 0.0 days, P = 0.01) across racial/ethnic groups, with African Americans (mean 6.6 days) and “Other” race/ethnicity (mean 6.9 days) PCC patients spending the most time hospitalized after discharge from index admission. Asian (mean 3.1 days), White (3.9 days), and Unknown race/ethnicity (2.0 days) PCC patients spent the fewest days hospitalized following discharge (P = 0.005).

Although DNR documentation significantly varied by race/ethnicity (sample mean 49%, P = 0.03), with White (51.2%) and Unknown race/ethnicity (56%) PCC patients documenting resuscitation wishes most prevalently, and Hispanic (32%) and Asian (35%) PCC patients documenting such preferences least commonly, the most interesting finding is that the proportion of PCC patient who were discharged to hospice did not significantly differ across racial/ethnic groups (P = 0.16). Racial/ethnic disparities in discharge to hospice did not differ by racial group among patients who received PCC. The majority of PCC patients (65%) changed their GOC during PCC, which might explain high hospice use across racial groups. Whether a patient changed GOC during PCC also did not significantly differ by PCC racial group (P = 0.14).

Discussion

This propensity-matched study found PCC is associated with statistically significant differences in 30-day readmissions, number of future days spent hospitalized, and accumulated mean future acute care costs (resulting in an average reduction of $8,704 per patient) in White patients, but no statistically significant differences in accumulated costs or acute care utilization in African Americans with PCC. It is unclear why these outcomes declined for White patients with PCC, but not African Americans with PCC. The higher proportion of White patients discharged to hospice from index admission (43% vs. 37%) may help explain some of these differences, as

hospice-eligible African American PCC patients not enrolled in hospice may have had greater or more frequent acute care utilization near EOL.[51,52] One recent study found that the effect of inpatient PCC on 30-day readmissions in oncology was largely driven by hospice enrollment, suggesting hospice may help explain some of our findings.[53] However, more research is needed to better understand why, when all available variables were held constant, PCC was associated with different cost and utilization outcomes among African American and White patients.

Differences in outcomes between African American and White PCC groups may be explained by variables not measured in our study. Socioeconomic variables such as income and education, which have been found to help explain differences in ACP in African Americans,[54] were not available in the dataset and may have contributed. Compared to Whites, African Americans endure significant systematic disadvantages resulting in disproportionate and poor economic resources to higher unemployment and lower incomes, which impact health, health literacy, and access to quality care.[54,55] Patients with lower levels of education have been found to have lower levels of health literacy,[54,56] which can influence how a patient understands, recalls, and applies information exchanged during PCC or other healthcare encounters.[56,57] Patients with lower health literacy have an increased risk of hospital admission,[58,59] use an inefficient mix of healthcare services,[60] and have higher healthcare costs,[60] all associations that may help explain why PCC among African Americans was not associated with acute care utilization and cost reductions.

Specifically, socioeconomic disadvantages may have contributed to avoidable use of the emergency department (ED). According to the literature, low socioeconomic status is independently associated with increased use of the ED, regardless of the visit or medical condition urgency.[61] Patients described as “working poor”[62] who do not qualify for Medicaid, patients without access to timely care in the community,[63] and patients with low health literacy who do not know how to navigate health resources[64] may visit the ED for possibly preventable care and subsequently be hospitalized.[64] Our study included the cost of ED visits that resulted in hospitalization, but excluded ED visits that did not involve inpatient care. It is therefore possible that patients who

visited the ED following discharge from an admission with PCC and were hospitalized for care that may have otherwise been treated in an outpatient setting also contributed to differences in future acute care cost totals among race-based PCC groups. Similarly, PCC patients without caregiver assistance may have increased ED use and hospitalization following discharge from index admission resulting in greater future costs,[65,66] although evidence is mixed on the role of informal caregivers and acute care costs.[66]

Religiosity, defined as strong religious beliefs, was not measured in the study but may have also contributed to outcome differences. Evidence suggests religiosity is associated with preferences for more treatment and life prolongation near EOL,[67] while religious coping is associated with receipt of intensive life-prolonging medical care near death.[68] African Americans' higher religiosity,[69] greater religious participation,[70] and greater reliance on support from church communities[70-72] are well-documented and may help explain why some utilization and cost outcomes did not differ among African American PCC and Non-PCC groups. African Americans' faith influences how they perceive hospice and EOL treatments[73] and greater deference to perceptions of God's will in healthcare decision-making is associated with stronger preferences for life-prolonging treatment,[74] possibly influencing our results. Although palliative care attends to the spiritual needs of patients, it is unknown if PCC reduces future acute care utilization in religious patients who do not enroll in hospice. And while African Americans' trust in their physicians may not be a significant factor in ACP involvement or preference for EOL treatments,[54] their greater dependence on church and community information when making healthcare decisions (compared to Whites who report primarily relying on healthcare providers)[71] may help explain why many PCC outcomes differed for Whites but not African Americans.

Race was not a factor in which patients received PCC in this medical center,[6] but study results for African Americans may be partially explained by possible disparities in concordance between care preferences expressed during PCC and actual care received during subsequent hospitalizations. One urban, academic study found that despite similar rates of EOL discussions

among African American and White cancer patients, African American patients tended to receive life-prolonging measures at EOL even when they had DNR orders or stated a preference for symptom-oriented care.[22] The study found EOL discussions helped White patients receive less life-prolonging EOL care, but that African American patients did not experience the same benefits.[22] More research is needed to better understand why these differences exist and how clinicians can help prevent them to reduce racial disparities in the care of persons with serious illness.

Intensive care unit utilization did not statistically differ between PCC/Non-PCC groups for either racial group when tiers were blended, suggesting some ICU care may be unavoidable.[75] Given nationwide increases in ICU use in the last 30 days of life among patients with serious illnesses[76] and one study's finding that 7% of ICU days are perceived as "futile,"[77] and therefore modifiable by PCC, it is possible that (despite matching for characteristics at the time of index admission) differences in the necessity and futility of future ICU use may have differed among PCC-race groups, also possibly contributing to cost findings among African Americans.[78]

Although acute care utilization and costs did not decline for African Americans with PCC, PCC was associated with a 15-fold increase in discharge to hospice among African American patients and a 14-fold increase among White patients. This is a remarkable finding given known racial/ethnic disparities in hospice use.[51,54,79,80] These figures do not include hospice use among patients who may have learned of hospice during PCC, then enrolled in hospice weeks or months after discharge from index admission. In theory, future hospice use may be even greater among PCC patients. These increases in hospice use suggest patients who received PCC and were discharged to hospice may have benefited from improved quality of life and symptom management, reduced suffering, and for those who later died, possibly better quality of death.[81] PCC's demonstrated ability to reduce racial disparities in hospice utilization make it an intervention worth expanding in populations with known differences in EOL care quality.

Although the majority of African American PCC patients (60.1%) and White PCC patients (67.7%) changed their goals-of-care during index admission during or following PCC, there was a

significant difference among the PCC groups (P = 0.01), suggesting unmeasured factors may influence PCC outcomes (**Table 3.1**). Even so, these high proportions suggest patient-provider PCC communication may have enabled patients make care decisions and may explain increases in hospice use across races and in DNR documentation (**Table 3.6**). Given that PCC has been shown to increase DNR documentation across racial groups, it is likely PCC in this study contributed to the increase in DNR orders.[82] Although DNR orders do not always ensure patients receive care concordant with their expressed preferences, DNRs are associated with higher quality of life near death[83] and reduced use of medical interventions near death,[84] which may suggest lower costs, possibly influencing our study results.

Finally, the comparison of outcomes across racial/ethnic groups of PCC patients highlights some important findings worth future investigation. Given racial disparities in hospice use,[35,36] it is remarkable that significant differences in discharge to hospice were not found across PCC racial/ethnic groups. Significant differences were also not found across PCC race/ethnicity groups for changes in GOC, suggesting PCC is effective in enabling patients to communicate care preferences and supporting decisions to enroll in hospice across race/ethnicity groups. Palliative care consultations may therefore be an intervention that helps reduce racial/ethnic disparities in the care of persons with serious illness. Significant differences in future acute care costs and utilization, notably the number of days hospitalized, did exist across PCC race/ethnicity groups, implying the need for more research to better understand if and how PCC differs across racial/ethnic groups, and whether other unmeasured factors influence findings.

Limitations

This study has several limitations. First, as is the case with all propensity-score studies, our models cannot account for unmeasured or unknown confounding variables.[6,85] We were unable to control for comorbidities, income, insurance status, education level, health literacy, religious beliefs, or duration of survival because these variables were not available in the dataset; dates of patient deaths outside the health system were unavailable. Unmeasured variables may

be distributed differently in patients who received PCC and those who did not (e.g., patients in one group may have died sooner than patients in another after discharge).[6]

In addition, diagnostic analysis of propensity score matching was not available, limiting understanding of how closely propensity tier groups matched on each of the ten specific variables. As with all propensity score matching studies with smaller samples, such as the PCC group in this study, it is difficult to perfectly match patients across a large number of variables.

When comparing the two groups of patients (those who had PCC and those who did not) using propensity scores, the groups should have similar propensities for having had a consult. As is standard, these propensities are determined through logistic regression models. In this study, there were separate models for Caucasian patients and for African-American patients, but the methodological approach and variables used were similar. Each propensity model featured as its dependent variable whether or not an individual had a palliative care consult (yes or no) and ten predictor variables (gender, age, disease severity, primary diagnosis, Medicaid status, direct cost of index admission, visitation by Oncology team, ICU admission, ICU admission for more than 6 days, and 30-day prior admission). Although patients in propensity-score matched PCC and Non-PCC groups may look different when it comes to some of the matching variables, what is important is that the groups have similar propensities for having PCC. We used a tiered approach, where we cut the data into six evenly-sized groups (based on propensity scores) but eliminated the lowest four propensity groups because those groups did not have enough patients with high propensity for PCC. The two highest propensity score tiers, which were used to assess outcomes, matched very well—both tiers have essentially identical minimums and maximums and similar mean propensities, indicating the groups can be compared. The similarity of these specific values increases confidence in the analysis.

Second, our analysis only examined acute care direct costs and healthcare utilization incurred within the health system after index hospitalization discharge.[6] Our analysis did not include costs incurred between hospitalizations or outside the health system (e.g., outpatient

care, skilled nursing care, homecare) or ED visits that did not result in hospitalization. The health system is the largest acute care provider in the Northeast, so few patients were likely admitted to hospitals outside the system, but even so we were unable to track costs of patients who were readmitted to local hospitals outside the hospital system.[6] Demographic and socioeconomic variables such as health literacy, religiosity, and marital status and clinical variables such as number of comorbidities, number of ED visits, and specific types of intensive interventions were unavailable in the dataset and therefore could not be analyzed. In addition, the variable 30-day readmissions only applies to patients still alive 30 days after discharge from index admission, which is not the entire sample population, as deaths among persons with serious illness occurred during the study period. Despite these limitations, study results may be used to show possible cost and utilization outcomes associated with PCC beyond the initial hospitalization among African Americans and among Whites in a sample matched, within racial group, on known covariates.[5,6,8]

Finally, our study examined a single academic medical center with high acuity and a well-established palliative care team and may not represent all hospitals caring for patients with serious illnesses. In the parent study at this medical center, race was not found to be a factor in whether or not patients received PCC.[6] However, the researchers did not investigate whether future acute care cost and utilization outcomes differed by race/ethnicity when PCC access is similar. Our study used robust measurement strategies to fill this gap. Depending on resources, training, culture, and patient population, PCC may also affect patients differently in other systems.[6] More research is needed to understand the influence of PCC on costs and healthcare utilization for specific racial/ethnic subgroups (e.g., Hispanics, Asians), which this analysis will be unable to address given smaller sample sizes for certain racial/ethnic populations. By studying the variable of race/ethnicity, our study provides more insight into future cost and healthcare utilization outcomes for African American patients who have or do not have PCC, and for White patients who have or do not have PCC while hospitalized. By comparing these outcomes among

propensity-matched White and African American patients with similar access to PCC, we were able to better understand associations between PCC and race/ethnicity on outcomes.

Ethical Considerations

Assessing acute care utilization and costs among different races raises ethical considerations. First, analyzing costs in the context of patient care may be perceived as a step toward rationing necessary healthcare among vulnerable persons. Although health systems benefit from reducing costs, saving money should never be the primary reason for engaging patients in PCC or making any clinical decisions.[86] Clinical decisions should be made with patient goals in mind and intentions to provide patients high quality of care, quality of life, and quality of death—outcomes associated with EOL discussions[11,81] and PCC.[87,88] Costs represent the kinds of care patients receive, with high EOL costs associated with worse quality of death.[12] Lower acute care costs represent less acute care utilization, which implies better quality of life for patients.[12] Palliative care consultation offers patients, clinicians, and payers the opportunity to uniquely increase patient autonomy, improve quality of care and quality of death, and reduce resource use.[89] Better communication about patient goals, values, prognosis, and treatment options benefits patients and tends to result in lower future acute care costs and admissions, benefiting patients and health systems alike. These mutual benefits clinically, financially, and ethically justify investment in PCC programs that aim to improve care for patients with serious illness.

Second, the goal of any racial disparities research in healthcare is to reduce disparities and improve care and quality for disadvantaged racial minorities. The results of our study suggest there are unmeasured factors influencing future acute care utilization and costs among African Americans who received PCC. More research is needed to better understand which modifiable variables influence the effectiveness of PCC among African Americans and the concordance of care preferences and future actual care provided in both community and acute care settings.

The results of our study have implications for patients, clinicians, healthcare systems, payers, and policy makers in the United States and beyond. As healthcare systems seek to provide evidence-based, patient-centered, cost-effective quality care to racially diverse patient populations with serious illness, including those near EOL, PCC appears to be an intervention that reduces costs and saves resources overall while improving quality outcomes such as hospice use across races and additional outcomes among White patients.

Conclusion

This is the first known study to quantify PCC cost savings across hospitalizations by race. These cost-savings and reductions in acute care use among Whites and, directionally yet not significantly, among African Americans justify the development of PCC programs that help patients better understand their illness, prognosis, and care options; and support patients' decisions to experience quality hospice care near EOL. Research is needed to explain why acute care utilization and cost disparities persist among African Americans despite PCC, and how clinicians can help overcome these disparities to provide high quality care for racial/ethnic minorities with serious illness.

Tables

Table 3.1 Description of Study Population

		Total N = 35,154	African Americans Non-PCC N = 10,777	African Americans with PCC N = 383	P value	Whites Non-PCC N =23,180	Whites with PCC N = 814	P value
Age (years)	18-39	5,739 (16%)	2385 (22.1%)	19 (5.0%)	**<.0001**	3280 (14.2%)	55 (6.8%)	**<.0001**
	40-45	2,419 (7%)	980 (9.1%)	4 (1.0%)		1405 (6.1%)	30 (3.7%)	
	46-50	2,642 (8%)	953 (8.8%)	21 (5.5%)		1639 (7.1%)	29 (3.6%)	
	51-55	3,614 (10%)	1215 (11.3%)	45 (11.8%)		2294 (9.9%)	60 (7.4%)	
	56-60	4,338 (12%)	1330 (12.3%)	55 (14.4%)		2854 (12.3%)	99 (12.2%)	
	61-65	4,320 (12%)	1165 (10.8%)	53 (13.8%)		2987 (12.9%)	115 (14.1%)	
	66-70	4,223 (12%)	955 (8.9%)	51 (13.3%)		3093 (13.3%)	124 (15.2%)	
	71-75	3,199 (9%)	668 (6.2%)	41 (10.7%)		2386 (10.3%)	104 (12.8%)	
	>75	4,660 (13%)	1126 (10.5%)	94 (24.5%)		3242 (14.0%)	198 (24.3%)	
Gender	Male	17,286 (49%)	4543 (42.2%)	172 (44.9%)	.2836	12148 (52.4%)	423 (52.0%)	0.80
	Female	17,868 (51%)	6234 (57.8%)	211 (55.1%)		11032 (47.6%)	391 (48.0%)	

		Total N = 35,154	African Americans Non-PCC N = 10,777	African Americans with PCC N = 383	P value	Whites Non-PCC N =23,180	Whites with PCC N = 814	P value
Medicaid	Yes	4,819 (14%)	3454 (32.0%)	83 (21.7%)	**<.0001**	1243 (5.4%)	39 (4.8%)	0.48
	No	30,335 (86%)	7323 (68.0%)	300 (78.3%)		21937 (94.6%)	775 (95.2%)	
Primary Diagnosis	Cancer	6,955 (19.8%)	1063 (9.9%)	103 (26.9%)	**<.0001**	5472 (23.6%)	317 (38.9%)	**<.0001**
	Cardiovascular disorder / Heart Failure	6,430 (18.3%)	1774 (16.5%)	76 (19.8%)		4444 (19.2%)	136 (16.7%)	
	Endocrine disorder	1,942 (5.5%)	902 (8.4%)	8 (2.1%)		1014 (4.4%)	18 (2.2%)	
	GI disorder	4,120 (11.7%)	1147 (10.6%)	29 (7.6%)		2872 (12.4%)	72 (8.9%)	
	Gynecologic or urologic disorder	2,393 (6.8%)	1086 (10.1%)	17 (4.4%)		1267 (5.5%)	23 (2.8%)	
	Infectious disease and Sepsis	2,950 (8.4%)	1227 (11.4%)	63 (16.5%)		1565 (6.8%)	95 (11.7%)	
	Neurologic disorder	3,508 (10%)	1204 (11.2%)	31 (8.1%)		2227 (9.6%)	46 (5.7%)	
	Respiratory disorder	1,394 (4.0%)	493 (4.6%)	23 (6.0%)		819 (3.5%)	59 (7.3%)	
	Other	5,462 (15.5%)	1881 (17.5%)	33 (8.6%)		3500 (15.1%)	48 (5.9%)	
APR-DRG Severity of Illness	Minor	8,044 (22.9%)	2343 (21.7%)	6 (1.6%)	**<.0001**	5680 (24.5%)	15 (1.8%)	**<.0001**
	Moderate	13,876 (39.5%)	4446 (41.3%)	36 (9.4%)		9316 (40.2%)	78 (9.6%)	
	Major	9,912 (28.2%)	3140 (29.1%)	167 (43.6%)		6270 (27.1%)	335 (41.2%)	

		Total N = 35,154	African Americans Non-PCC N = 10,777	African Americans with PCC N = 383	P value	Whites Non-PCC N =23,180	Whites with PCC N = 814	P value
	Severe	3,322 (9.4%)	848 (7.9%)	174 (45.4%)		1914 (8.3%)	386 (47.4%)	
APR-DRG Risk of Mortality	Minor	15,914 (45.3%)	5142 (47.7%)	11 (2.9%)	**<.0001**	10741 (46.3%)	20 (2.5%)	**<.0001**
	Moderate	10,112 (28.8%)	3072 (28.5%)	50 (13.1%)		6854 (29.6%)	136 (16.7%)	
	Major	6,637 (18.9%)	1940 (18.0%)	179 (46.7%)		4177 (18.0%)	341 (41.9%)	
	Severe	2,491 (7.1%)	623 (5.8%)	143 (37.3%)		1408 (6.1%)	317 (38.9%)	
Acute care hospitalization 30 days prior to index hospitalization	Yes	653 (1.9%)	127 (1.2%)	80 (20.9%)	**<.0001**	240 (1.0%)	206 (25.3%)	**<.0001**
	No	34,501 (98.1%)	10650 (98.8%)	303 (79.1%)		22940 (999.0%)	608 (74.7%)	
ICU care during index admission	Yes	11,448 (32.6%)	2792 (25.9%)	197 (51.4%)	**<.0001**	8025 (34.6%)	434 (53.3%)	**<.0001**
	No	23,706 (67.4%)	7985 (74.1%)	186 (48.6%)		15155 (65.4%)	380 (46.7%)	
ICU care > 6 days during index admission	Yes	2,637 (7.5%)	624 (5.8%)	104 (27.2%)	**<.0001**	1683 (7.3%)	226 (27.8%)	**<.0001**
	No	32,517 (92.5%)	10153 (94.2%)	279 (72.8%)		21497 (92.7%)	588 (72.2%)	
Visited by Oncology service during index admission (1st or 2nd service)	Yes	2,984 (8.5%)	456 (4.2%)	77 (20.1%)	**<.0001**	2188 (9.4%)	263 (32.3%)	**<.0001**
	No	32,170 (91.5%)	10321 (95.8%)	306 (79.9%)		20992 (90.6%)	551 (67.7%)	

		Total N = 35,154	African Americans Non-PCC N = 10,777	African Americans with PCC N = 383	P value	Whites Non-PCC N =23,180	Whites with PCC N = 814	P value
DNR documented during index admission	Yes	1,425 (4.1%)	242 (2.2%)	172 (44.9%)	**<.0001**	594 (2.6%)	417 (51.2%)	**<.0001**
	No	33,729 (95.9%)	10535 (97.8%)	211 (55.1%)		22586 (97.4%)	397 (48.8%)	
Mean number of days hospitalized during index admission (SD)			5.96 (7.63)	17.05 (19.5)	**<.0001**	6.29 (7.67)	16.53 (19.06)	**<.0001**
Median number of days hospitalized during index admission (IQR)			4.0 (2.0-7.0)	10.0 (6.0-20.0)	**<.0001**	4.0 (2.0-7.0)	10.0 (6.0-20.0)	**<.0001**
- Mean number of ICU days during index admission (SD)			1.18 (4.26)	6.03 (12.70)	**<.0001**	1.45 (4.00)	6.36 (13.78)	**<.0001**
Median number of ICU days during index admission (IQR)			0 (0-0)	1.0 (0-6.0)	**<.0001**	0 (0-1.0)	1.0 (0-7.0)	**<.0001**
Mean direct acute care costs during index admission (SD)			$15665 ($22667)	$35982 ($49024)	**<.0001**	$19583 ($25209)	$40126 ($59607)	**<.0001**
Median direct acute care costs during index admission (IQR)			$9,723 ($5,898-$15,641)	$18,578 ($10,811-$38,119)	**<.0001**	$12,114 ($7,639-$21,373)	$20,017 ($10,455-$41,445)	**<.0001**
Changed goals-of-care during PCC index admission (% yes)			n/a	60.1%	**-**	n/a	67.7%	**0.01**

Significance tests for the percentage variables involved a Chi-squared test; significance tests for parametric continuous variables involved a t test; significance tests for non-parametric continuous variables involved a Kruskal-Wallis non-parametric test of ranks.

Table 3.2 Logistic Regression Analysis of Likelihood of Receiving Palliative Care Consult

		African American patients			White patients		
Parameter		**Estimate**	**SE**	**P value**	**Estimate**	**SE**	**P value**
Intercept		-2.0415	0.1688	**<.0001**	-1.8617	0.1351	**<.0001**
Age (years)	18-39	-0.858	0.212	**<.0001**	-0.315	0.133	**0.018**
	40-55	-0.189	0.128	0.139	-0.148	0.094	0.113
	56-65	0.222	0.113	**0.0497**	0.119	0.077	0.123
	66-75	0.077	0.126	0.544	-0.013	0.078	0.872
	>75	0	-	-	0	-	-
Gender	Male	-0.0548	0.0593	0.356	-0.1562	0.0407	**0.0001**
	Female	0	-		0	-	
Medicaid*	Yes	0.114	0.082	0.164	0.141	0.095	0.139
	No	0	-		0	-	
Primary Diagnosis	Cancer	0	-		0	-	-
	Cardiovascular disorder and Heart Failure	-0.100	0.137	0.467	-0.492	0.102	**<.0001**
	Endocrine disorder	-0.449	0.334	0.18	0.082	0.235	0.727
	GI disorder	-0.011	0.203	0.956	0.066	0.130	0.612
	Gynecologic or urologic disorder	-0.193	0.247	0.436	-0.260	0.215	0.2259
	Infectious disease and Sepsis	-0.070	0.151	0.641	0.016	0.120	0.891
	Neurologic disorder	-0.370	0.193	0.056	-0.254	0.154	0.099
	Respiratory disorder	0.282	0.282	0.199	0.615	0.148	**<.0001**
	Other	-0.130	0.186	0.484	-0.288	0.153	0.059
APR-DRG Risk of Mortality	Minor	-2.129	0.239	**<.0001**	-2.371	0.176	**<.0001**
	Moderate	-0.602	0.141	**<.0001**	-0.423	0.094	**<.0001**
	Major	0.988	0.111	**<.0001**	1.013	0.080	**<.0001**
	Severe	0	-	-	0	-	-

		African American patients			White patients		
ICU during index admission	Yes	0.138	0.066	**0.036**	0.149	0.043	**0.0005**
	No	0	-		0	-	
ICU > 6 days during index admission	Yes	0.232	0.090	**0.01**	0.265	0.056	**<.0001**
	No	0	-		0	-	
Seen by Oncology in index admission	Yes	0.284	0.088	**0.001**	0.266	0.051	**<.0001**
	No	0	-		0	-	
Admitted to hospital 30 days prior	Yes	1.435	0.097	**<.0001**	1.589	0.064	**<.0001**
	No	0	-		0	-	
Direct Cost of index admission (impact per $1,000) *		$2.92*10^{-3}$	$1.52*10^{-3}$	.0535	$1.72*10^{-3}$	$9.55*10^{-4}$	0.072

Abbreviation: SE, standard error

* For every increase of $1000 in direct costs, the estimate shows the expected increase in getting a palliative care consult.

Table 3.3 Propensity Scores Ranked from Highest to Lowest Tiers, by Race

Propensity Scores Ranked Highest to Lowest, African American patients								
	Patients with Palliative Care Consult,[1] n = 383				**Patients without Palliative Care Consult,[1] n = 10,777**			
Tier	**Propensity Score Mean**	**n**	**Min,**	**Max**	**Propensity Score Mean**	**n**	**Min,**	**Max**
Highest	0.303	178	0.202	0.481	0.276	1,667	0.202	0.498
2nd Highest	0.134	129	0.078	0.201	0.114	1,717	0.073	0.202
	0.061	18	0.042	0.073	0.058	1,827	0.04	0.073
Middle	0.024	10	0.015	0.033	0.021	1,836	0.014	0.040
	0.010	1	0.01	0.01	0.012	1,844	0.009	0.014
Lowest	-	0	-	-	0.006	1,845	0.004	0.009
Propensity Scores Ranked Highest to Lowest, White patients								
	Patients with Palliative Care Consult,[1] n = 814				**Patients without Palliative Care Consult,[1] n = 23,180**			
Tier	**Propensity Score Mean**	**n**	**Min,**	**Max**	**Propensity Score Mean**	**n**	**Min,**	**Max**
Highest	0.331	350	0.212	0.498	0.298	3,604	0.212	0.498
2nd Highest	0.153	257	0.097	0.212	0.141	3,698	0.096	0.212
	0.061	55	0.062	0.096	0.080	3,900	0.061	0.096
Middle	0.039	19	0.015	0.061	0.028	3,935	0.014	0.061
	0.013	1	0.0126	0.0126	0.012	3,954	0.011	0.014
Lowest	0.010	2	0.0099	0.0105	0.009	3,952	0.006	0.011

[1] Palliative care consult to discuss goals-of-care

Table 3.4 Future Costs, Healthcare Utilization, and Discharge to Hospice After Propensity Score Matching, African American patients.

African American patients	**Propensity Group** Highest Tier (n)[a] Second Highest Tier (n)[a] Top Two Tiers Blended (n)[a]	**PCC** n = 178 n = 129 n = 307	**Non-PCC** n = 1,667 n = 1,717 n = 3,384	**P value** [b]
Primary Outcomes: Future costs				
Did patient have any future acute care costs? (% yes)	Highest propensity group	33.7%	38.0%	0.26
	Second highest propensity group	29.5%	37.3%	0.08
	Top Two Tiers Blended	31.9%	37.7%	**0.047**
Mean accumulated future acute care costs (SD)	Highest propensity group	$11,452 ($26,684)	$15,867 ($45,316)	0.055
	Second highest propensity group	$11,925 ($40,709)	$14,256 ($36,670)	0.53
	Top Two Tiers Blended	$11,651 ($33,244)	$15,050 ($41,158)	0.09
Secondary Outcomes: Future healthcare utilization				
Was the patient admitted within 30 days? (% yes)	Highest propensity group	15.7%	16.3%	0.84
	Second highest propensity group	17.8%	14.6%	0.31
	Top Two Tiers Blended	16.6%	15.4%	0.58
Mean number of days in hospital post-discharge (SD)	Highest propensity group	5.47 (10.86)	6.72 (17.2)	0.18
	Second highest propensity group	5.45 (18.84)	6.00 (13.99)	0.74
	Top Two Tiers Blended	5.46 (14.72)	6.35 (15.66)	0.34
Was the patient admitted to ICU post-discharge (% yes)	Highest propensity group	17.4%	15.8%	0.58
	Second highest propensity group	15.5%	12.6%	0.34
	Top Two Tiers Blended	16.6%	14.2%	0.25
Mean number of ICU days post-discharge (SD)	Highest propensity group	1.27 (4.17)	1.18 (7.03)	0.81
	Second highest propensity group	1.29 (5.14)	0.80 (3.25)	0.28
	Top Two Tiers Blended	1.28 (4.60)	0.99 (5.45)	0.30
Discharge to hospice from index admission (% yes)	Highest propensity group	30.3%	2.6%	<.0001
	Second highest propensity group	45.0%	2.3%	<.0001
	Top Two Tiers Blended	36.5%	2.4%	**<.0001**

[a] Sample sizes are consistent within each column (across all outcome variables).[b] Significance tests for the percentage variables involved a Cochran-Mantel-Haenszel test; significance tests for the continuous variables involved a pooled t test. SD is standard deviation

Table 3.5 Future Costs, Acute Care Utilization, and Discharge to Hospice After Propensity Score Matching, White patients.

White patients	**Propensity Group** Highest Tier (n)[a] Second Highest Tier (n)[a] Top Two Tiers Blended (n)[a]	**PCC** n = 350 n = 257 n = 607	**Non-PCC** n = 3,604 n = 3,698 n = 7,302	**P value**[b]
Primary Outcomes: Future costs				
Did patient have any future acute care costs? (% yes)	Highest propensity group	24.5%	33.9%	**0.008**
	Second highest propensity group	24.5%	37.2%	**<0.0001**
	Top Two Tiers Blended	**25.9%**	**35.5%**	**<0.0001**
Mean accumulated future acute care costs (SD)	Highest propensity group	$8,302 ($11,237)	$14,995 ($16,347)	**<0.0001**
	Second highest propensity group	$7,813 ($25,617)	$18,558 ($47,998)	**<0.0001**
	Top Two Tiers Blended	$8,095 ($26,947)	$16,799 ($44,898)	**<0.0001**
Secondary Outcomes: Future acute care utilization				
Was the patient admitted within 30 days? (% yes)	Highest propensity group	11.4%	15.8%	**0.032**
	Second highest propensity group	8.6%	17.6%	**0.0002**
	Top Two Tiers Blended	10.2%	16.7%	**<0.0001**
Mean number of days in hospital post-discharge (SD)	Highest propensity group	3.56 (10.88)	5.66 (14.16)	**0.0009**
	Second highest propensity group	3.86 (13.61)	6.97 (16.90)	**0.0006**
	Top Two Tiers Blended	3.69 (12.11)	6.32 (15.62)	**<0.0001**
Was the patient admitted to ICU post-discharge (% yes)	Highest propensity group	12.0%	13.9%	0.331
	Second highest propensity group	13.2%	14.9%	0.459
	Top Two Tiers Blended	12.5%	14.4%	0.202
Mean number of ICU days post-discharge (SD)	Highest propensity group	0.61 (2.33)	0.90 (4.25)	**0.042**
	Second highest propensity group	1.00 (4.18)	1.06 (4.79)	0.849
	Top Two Tiers Blended	0.78 (3.25)	0.98 (4.53)	0.154
Discharge to hospice from index admission (% yes)	Highest propensity group	41.1%	3.3%	**<0.0001**
	Second highest propensity group	44.8%	2.8%	**<0.0001**
	Top Two Tiers Blended	42.7%	3.0%	**<0.0001**

[a] Sample sizes are consistent within each column (across all outcome variables). [b] Significance tests for the percentage variables involved a Cochran-Mantel-Haenszel test; significance tests for the continuous variables involved a pooled t test.

Table 3.6 DNR Documentation among African Americans and Whites with or without Palliative Care Consultation

	Propensity Group Highest Tier (n)[a] Second Highest Tier (n)[a] Top Two Tiers Blended (n)[a]	**African American with PCC** n = 178 n = 129 n = 307	**African American Non-PCC** n = 1,667 n = 1,717 n = 3,384	**P value[b]**	**White with PCC** n = 350 n = 257 n = 607	**White Non-PCC** n = 3,604 n = 3,698 n = 7,302	**P value[b]**
DNR documented during index admission (% yes)	Highest propensity group	42.7%	5.6%	**<.0001**	50.3%	7.5%	**<.0001**
	Second highest propensity group	49.6%	4.7%	**<.0001**	58.4%	5.1%	**<.0001**
	Top Two Tiers Blended	45.6%	5.2%	**<.0001**	53.7%	6.3%	**<.0001**

[a] *Sample sizes are consistent within each column (across all outcome variables).*
[b] *Significance tests for the percentage variables involved a Cochran-Mantel-Haenszel test.*

Table 3.7 Description of Asians (alive at the time of discharge from index admission) with and without PCC

** Groups were not propensity-score matched.*

Outcomes (Sample not propensity-score matched)	**Asians with PCC N = 48**	**Asians without PCC N = 913**	**Asians Total N = 961**	***P* value**
Index admission: Mean number of days hospitalized (SD)	18.0 (24.9)	6.3 (8.4)	6.88 (10.2)	**<0.0001**
Index admission: Median number of days hospitalized (IQR)	7.0 (13.0)	4.0 (5.0)	4.0 (5.0)	**<0.0001**
Index admission: Mean number of ICU days (SD)	10.2 (20.6)	1.2 (3.8)	1.6 (6.2)	**<0.0001**
Index admission: Median number of ICU days (IQR)	1.5 (8.5)	0.0 (1.0)	0.0 (1.0)	**<0.0001**
Index admission: Mean direct acute care costs (SD)	$46,766 ($81,216)	$18,875 ($26,570)	$20,268 ($32,102)	**<0.0001**
Index admission: Median direct acute care costs (IQR)	$14,739 ($24,510)	$10,805 ($12,190)	$10,969 ($12,628)	**.002**
Future: Any future acute care costs post-discharge (% yes)	27.1%	25.3%	25.4%	0.78
Future: Mean total direct acute care costs post-discharge (SD)	$6,893 ($16,778)	$9,874 ($33,927)	$9,725 ($33,282)	0.55
Future: Median total direct acute care costs post-discharge (IQR)	$0 ($0-$1,560)	$0 ($0-$2,755)	$0 ($0-$2,049)	0.86
Future: Any ICU days post-discharge (% yes)	14.6%	8.7%	9.0%	0.16
Future: Readmitted within 30 days (% yes)	14.6%	11.1%	11.2%	0.45
Future: Mean number hospital days following index admission (SD)	3.08 (8.0)	3.8 (12.5)	3.8 (12.3)	0.70
Future: Median number hospital days following index admission (IQR)	0.0 (0-2)	0.0 (0-1)	0.0 (0-1)	0.84
Future: Mean number ICU days following index admission (SD)	0.77 (2.1)	0.70 (4.3)	0.67 (4.2)	0.87
Future: Median number ICU days following index admission (IQR)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	0.16
Discharged to hospice from index admission (% yes)	33.3%	0.8%	2.4%	**<0.0001**
DNR documented during index admission (% yes)	35.4%	1.5%	3.2%	**<0.0001**
Changed goals-of-care during palliative care consult (% yes)	**58.3%**	-	-	-

Percentage variables analyzed using a Chi-squared test. Continuous parametric variables were analyzed using a Two-sample t test with equal variances. Continuous non-parametric variables were analyzed using a Mann–Whitney U-test.

Table 3.8 Description of Hispanics (alive at the time of discharge from index admission) with and without PCC

** Groups were not propensity-score matched.*

Outcomes (Sample not propensity-score matched)	**Hispanics with PCC N = 22**	**Hispanics without PCC N = 829**	**Hispanics Total N = 851**	***P* value**
Index admission: Mean number of days hospitalized (SD)	17.8 (17.6)	5.85 (7.1)	6.16 (7.8)	**<0.0001**
Index admission: Median number of days hospitalized (IQR)	9.0 (17.0)	4.0 (4.0)	4.0 (5.0)	**<0.0001**
Index admission: Mean number of ICU days (SD)	5.22 (10.1)	1.2 (3.3)	1.2 (3.7)	**<0.0001**
Index admission: Median number of ICU days (IQR)	0.0 (0-7.0)	0.0 (0-1.0)	0.0 (0-1.0)	**0.03**
Index admission: Mean direct acute care costs (SD)	$38,739 ($45,258)	$18,332 ($26,403)	$18,859 ($27,207)	**0.0005**
Index admission: Median direct acute care costs (IQR)	$18,907 ($33,937)	$10,635 ($12,207)	$10,801 ($12,702)	**0.002**
Future: Any future acute care costs post-discharge (% yes)	36.4%	25.6%	25.9%	0.25
Future: Mean total direct acute care costs post-discharge (SD)	$7,800 ($14,007)	$11,435 ($42,366)	$11,341 ($41,876)	0.69
Future: Median total direct acute care costs post-discharge (IQR)	$0 (14,257)	$0 ($3,762)	$0 ($3779)	0.32
Future: Any ICU days post-discharge (% yes)	13.6%	9.7%	9.8%	0.53
Future: Readmitted within 30 days (% yes)	18.2%	11.6%	11.8%	0.34
Future: Mean number hospital days following index admission (SD)	4.05 (6.3)	4.18 (13.5)	4.18 (13.4)	0.96
Future: Median number hospital days following index admission (IQR)	0.0 (0-9.0)	0.0 (0-1.0)	0.0 (0-1.0)	0.13
Future: Mean number ICU days following index admission (SD)	1.05 (3.2)	0.80 (5.1)	0.81 (5.1)	0.82
Future: Median number ICU days following index admission (IQR)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	0.48
Discharged to hospice from index admission (% yes)	31.8%	0.4%	1.2%	**<0.0001**
DNR documented during index admission (% yes)	31.8%	0.97%	1.8%	**<0.0001**
Changed goals-of-care during palliative care consult (% yes)	**59.1%**	-		-

Percentage variables analyzed using a Chi-squared test. Continuous parametric variables were analyzed using a Two-sample t test with equal variances. Continuous non-parametric variables were analyzed using a Mann–Whitney U-test.

Table 3.9. Description of "Other" race/ethnicity patients (alive at the time of discharge from index admission) with and without PCC
** Groups were not propensity-score matched. This sample includes patients who self-reported as American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander, or "Other"* race/ethnicity.

Outcomes (Sample not propensity-score matched)	**"Other" Race/Ethnicity with PCC N = 39**	**"Other" Race/Ethnicity without PCC N = 1,095**	**"Other" Race/Ethnicity Total N = 1,134**	***P* value**
Index admission: Mean number of days hospitalized (SD)	20.5 (33.7)	7.2 (9.7)	7.7 (11.6)	**<0.0001**
Index admission: Median number of days hospitalized (IQR)	10.0 (16.0)	4.0 (6.0)	5.0 (6.0)	**<0.0001**
Index admission: Mean number of ICU days (SD)	6.9 (12.3)	1.9 (5.9)	2.0 (6.3)	**<0.0001**
Index admission: Median number of ICU days (IQR)	2.0 (10.0)	0.0 (1.0)	0.0 (2.0)	**<0.0001**
Index admission: Mean direct acute care costs (SD)	$43,376 ($57,448)	$21,258 ($35,946)	$22,019 ($37,075)	**0.0002**
Index admission: Median direct acute care costs (IQR)	$20,540 ($38,849)	$11,382 ($15,450)	$11,508 ($15,950)	**0.0003**
Future: Any future acute care costs post-discharge (% yes)	30.8%	23.3%	23.5%	0.28
Future: Mean total direct acute care costs post-discharge (SD)	$14,693 ($30,331)	$7,227 ($26,848)	$7,483 ($26,995)	0.09
Future: Median total direct acute care costs post-discharge (IQR)	$0 ($0-$13,980)	$0 ($0)	$0 ($0)	0.13
Future: Any ICU days post-discharge (% yes)	15.4%	7.3%	7.6%	0.06
Future: Readmitted within 30 days (% yes)	15.4%	12.1%	12.2%	0.53
Future: Mean number of hospital days following index admission (SD)	6.9 (13.4)	2.7 (9.3)	2.9 (9.5)	**0.007**
Future: Median number of hospital days following index admission (IQR)	0.0 (7.0)	0.0	0.0 (0.0)	0.10
Future: Mean number of ICU days following index admission (SD)	1.0 (3.5)	0.65 (5.5)	0.66 (5.5)	0.67
Future: Median number of ICU days following index admission (IQR)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	0.06
Discharged to hospice from index admission (% yes)	28.2%	1.6%	2.5%	**<0.0001**
DNR documented during index admission (% yes)	46.2%	3.5%	4.9%	**<0.0001**
Goals-of-care changed during palliative care consult (% yes)	69.2%	-	-	-

Percentage variables analyzed using a Chi-squared test. Continuous parametric variables were analyzed using a Two-sample t test with equal variances. Continuous non-parametric variables were analyzed using a Mann–Whitney U-test.

Table 3.10 Comparison of groups receiving palliative care consultation (PCC) for goals-of-care/end-of-life by race/ethnicity

PCC Comparison by Race	All PCC Patients N= 1,390	Asians with PCC N = 48	African Americans with PCC N = 383	Hispanics with PCC N = 22	Whites with PCC N= 814	"Other" Ethnicity w/ PCC N = 39	Unknown Ethnicity with PCC N = 84	P value
Index admission: Mean number of days hospitalized (SD)**	17.1 (19.9)	18.0 (24.9)	17.0 (19.5)	17.8 (17.6)	16.5 (19.0)	20.5 (33.7)	19.8 (18.3)	0.62
Index admission: Median number of days hospitalized (IQR)***	10.0 (15.0)	7.0 (13.0)	10.0 (14.0)	9.0 (17.0)	10.0 (14.0)	10.0 (16.0)	14.5 (18.5)	0.19
Index admission: Mean number of ICU days (SD)**	6.7 (13.9)	10.2 (20.6)	6.0 (12.7)	5.2 (10.1)	6.4 (13.8)	6.9 (12.3)	10.6 (16.2)	**0.04**
Index admission: Median number of ICU days (IQR)***	1.0 (8.0)	1.5 (8.5)	1.0 (6.0)	0.0 (7.0)	1.0 (7.0)	2.0 (10.0)	3.0 (15.0)	0.11
Index admission: Mean direct acute care costs (SD)**	$40,140 ($58,073)	$46,766 ($81,216)	$35,982 ($49,024)	$38,739 ($45,258)	$40,125 ($59,607)	$43,376 ($57,448)	$54,307 ($67,052)	0.17
Index admission: Median direct acute care costs (IQR)***	$19,713 ($31,212)	$14,739 ($24,510)	$35,982 ($18,578)	$28,907 ($33,937)	$20,017 ($30,991)	$20,540 ($38,849)	$27,311 ($53,322)	**0.04**
Future: Any future acute care costs post-discharge (% yes)*	28.2%	27.1%	34.7%	36.4%	26.2%	30.8%	15.5%	**0.004**
Future: Total mean direct acute care costs post-discharge (SD)**	$9,616 ($28,720)	$6,893 ($16,778)	$13,162 ($34,129)	$7,800 ($14,007)	$8,384 ($27,223)	$14,694 ($30,331)	$5,052 ($21,047)	**0.047**
Future: Median total direct acute care costs post-discharge (IQR)***	$0.00 ($2,005)	$0.00 ($1,560)	$0.00 (11,144)	$0.00 ($14,257)	$0.00 ($855)	$0.00 ($13,978)	$0.00 ($0.00)	**0.02**
Future: Readmitted within 30 days (% yes)*	13.3%	14.6%	18.3%	18.2%	11.6%	15.4%	4.8%	**0.006**
Future: Mean total number of hospital days following index admission (SD)**	4.5 (13.3)	3.1 (8.0)	6.6 (16.8)	4.1 (6.3)	3.9 (12.0)	6.9 (13.4)	2.0 (9.7)	**0.005**
Future: Median total number of hospital days following index admission (IQR)***	0.0 (1.0)	0.0 (2.0)	0.0 (6.0)	0.0 (9.0)	0.0 (1.0)	0.0 (7.0)	0.0 (0.0)	**0.01**
Future: Any ICU days post-discharge (% yes)*	13.9%	14.6%	18.0%	13.6%	12.7%	15.4%	6.0%	0.051

PCC Comparison by Race	All PCC Patients N= 1,390	Asians with PCC N = 48	African Americans with PCC N = 383	Hispanics with PCC N = 22	Whites with PCC N= 814	"Other" Ethnicity w/ PCC N = 39	Unknown Ethnicity with PCC N = 84	P value
Future: Mean total number of ICU days following index admission (SD)**	1.0 (4.2)	0.77 (2.1)	1.50 (5.8)	1.05 (3.2)	0.82 (3.5)	1.03 (3.5)	0.59 (3.2)	0.22
Future: Median number of total ICU days following index admission (IQR)***	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)	0.54
Discharged to hospice from index admission (% yes) *	39.1%	33.3%	35.5%	41.2%	28.2%	28.2%	45.2%	0.16
DNR documented during index admission (% yes) *	48.8%	35.4%	44.9%	31.8%	51.2%	46.2%	56.0%	**0.03**
Goals-of-care changed during palliative care consult (% yes) *	65.0%	58.3%	60.1%	59.1%	67.7%	69.2%	65.5%	0.14

IQR: Inter quartile range.
**Percentage variables analyzed using a Chi-squared test.*
***Parametric continuous variables were analyzed using one-way ANOVA.*
****The Kruskal-Wallis test was used for non-parametric continuous data.*

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CHAPTER FOUR: RISK FACTOR PROFILES ASSOCIATED WITH PALLIATIVE CARE CONSULTATIONS BEFORE DEATH

Abstract

Background: Previous studies show benefits of having early palliative care consultations (PCC) to discuss goals-of-care (GOC) with seriously ill patients. To help clinicians identify patients at-risk for late PCC, it is important to understand risk factor profiles associated with the timing of these conversations in hospital settings where late conversations are more likely to occur.

Objective: To identify risk factor profiles associated with the timing of inpatient PCC before death (0-14 days before death, 15-60 days before death, > 60 days before death) using available clinical, demographic, and administrative variables.

Design: Secondary analysis of an observational, retrospective cohort study involving supplementary de-identified patient data.

Sample and Setting: This study was conducted using preexisting clinical and administrative data from a large, urban, academic medical center in the Northeast region. Supplementary data (Medicaid status and days between PCC and death) was extracted from electronic medical records and matched to unique patient identifiers. The sample included 1,141 patients age 18+ who were admitted to the medical center, had PCC, and died between July 1, 2014 to October 31, 2016 (PCC 0-14 days before death, n = 612; PCC 15-60 days before death, n = 292; PCC > 60 days before death, n = 237). Patients who were admitted for childbirth or rehabilitation, and patients whose date of death was unknown were excluded.

Measurements and Analysis: Adjusted multinomial logistic regression was used to identify variables associated with the timing of PCC. Variables included age, gender, race/ethnicity, Medicaid status, primary diagnosis, source of referral to palliative care, APR-DRG Severity of Illness (physiological decomposition), APR-DRG Risk of Mortality (likelihood patient will die), intensive care unit (ICU) use during index admission, ICU use greater than six days during

index admission, visitation by Oncology services during index admission, and source of referral to palliative care. Regression results were used to develop a Classification and Regression Tree (CART) model to identify risk factor profiles based on complex variable interactions associated with the timing of PCC before death.

Results: Over half (54%) of patients received PCC “close to death” (0-14 days before death), 26% received “moderately-timed” PCC (15-60 days before death) and 21% received “early” PCC (>60 days before death). The median PCC was 13 days before death. No evidence of multicollinearity was found among variables. Adjusted multinomial logistic regression identified no variables with significant differences across the three PCC timing groups overall. However, compared to patients over age 75, patients aged 56-60 were almost twice as likely to have consults close to death relative to early (OR = 1.94, 95% Confidence Interval 1.09, 3.47; P=0.03), with no significant difference for moderately-timed PCC relative to early. Compared to referrals from Oncology specialists, patients referred to PCC by General Medicine/Hospitalists were twice as likely to have consults close to death relative to early (OR = 2.02, 95% Confidence Interval 1.16, 3.53; P = 0.01), with no significant difference for moderately-timed PCC relative to early. The CART model was effective at identifying which patients received PCC 0-14 days before death (88.2% sensitivity), but not which patients received PCC 15-60 days before death (27.4%) or PCC > 60 days before death (1.7%). The model was effective at identifying which patients did not receive early or moderately-timed PCC (specificity 99.1% and 82.1%, respectively). Patients with extreme illness severity who were in the ICU and were Hispanic or “Other” racial/ethnic minority were more likely to receive PCC close to death (85%); age under 46 or older than 75 further increased this probability (98%). On the other hand, patients with non-extreme illness severity who were not in the ICU were least likely to receive PCC close to death (24%). ICU patients with extreme illness severity were more likely to receive PCC close to death (64%), but 50% of ICU patients with less than extreme severity of illness also received PCC within 14 days of death.

Conclusion: In this secondary analysis, a majority of patients with serious illness (e.g., cancer, cardiovascular disease, etc.) received PCC close to death. A complex set of variable interactions were associated with the timing of PCC. A systematic process for engaging patients with PCC earlier in the care continuum, and especially in the ICU regardless of illness severity, is needed.

Introduction

As medicine and technology advance and providers are able to alter the normal dying process with life-extending treatments, patients with serious illness and their families are increasingly tasked with making difficult decisions about end-of-life (EOL) care.[1] Although less aggressive EOL care is often preferred[2-4] and is associated with family perceptions of higher quality care and lower regret,[5,6] hospitals' default mechanism to maintain life often results in patients receiving intensive, sometimes unnecessary, care near death.[7] Evidence suggests a majority of patients receive intensive care unit (ICU) treatment within six months of dying[8] and up to 38% of patients receive non-beneficial treatments near EOL, which may alter quality of life.[7]

Patient-provider discussions about goals-of-care (GOC) and EOL, including conversations that occur during palliative care consultations (PCC), enable providers to understand patient values and needs, help patients make informed decisions about their care experience before dying,[9] and are associated with patients receiving the kind of care they prefer at EOL.[10-12] Patients who have PCC are almost seven times more likely to document advance care planning wishes than patients who do not have PCC,[13] which may further help achieve care concordant with preferences.[11,14] These conversations are also associated with less aggressive treatments and lower use of intensive care, [9,11,15-18] lower 30-day readmission rates and hospitalizations overall,[9,16,17,19] fewer in-hospital deaths and greater utilization of hospice, [10,15-18,20] and higher quality EOL care.[18,21] Perhaps as a result of supporting patients who choose less aggressive care near EOL, these discussions are also associated with lower EOL costs,[16,22-27] which evidence suggests is associated with better quality of death.[17] When patients have these important discussions and receive the EOL care they prefer, lower costs often follow, benefiting patients and health systems alike.[28]

Palliative care consultations offer many communication and clinical benefits, such as improving pain and symptom management and increasing advance care planning,[16,22,24-26,29-32] but the timing of these consultations matters.[33-37] Earlier care planning conversations are associated with greater quality of life near EOL and may help patients receive care more

consistent with preferences.[18,21,38,39] Later GOC discussions are associated with greater risk of aggressive care, hospital death, and odds of ICU admission.[18] Specifically, PCC < 90 days before death—timing that most typically occurs in hospital settings—is associated with higher rates of inpatient, ICU, and emergency department care in the last month of life, and higher direct inpatient costs in the last six months of life ($6,687 difference per person) compared to PCC occurring more than 90 days before death.[36] Higher EOL costs reflect greater use of acute and intensive services, which are associated with worse quality of death.[17] If care planning and EOL discussions occur close to death, patients may make pressured decisions leading to care that is not concordant with their preferences.[15,40,41]

In one study of advanced heart failure patients, PCC to discuss GOC during terminal hospital admission was often either absent or very near death, with a median time of six days between PCC and death and only 24 hours between orders for comfort care and death.[42] The timing is not much better among persons with other serious illnesses.[12] Patients with cancer experience the most timely consultations, a median of 16-33 days before death depending on cancer type and other factors.[15,43,44] Each additional day from hospital admission to care planning conversation has been found to be associated with a 4% increased risk of aggressive interventions and in-hospital death, and 19% greater odds of intensive care unit (ICU) admission.[18] Early discussion of prognosis and EOL care options facilitates earlier enrollment in hospice and earlier use of palliative care services,[45] which are associated with quality care.[33,46] When care planning discussions occur close to death, or not at all, patients may not receive the benefits of comfort care as early as they might have liked, possibly resulting in greater regret about care decisions.[6] Evidence suggests racial/ethnic minorities are less likely than Whites to have these conversations with healthcare providers,[47-52] but for minority patients who do have these conversations, such as during PCC in which race may not be a factor,[16] little is known about their timing. Unfortunately, 84% of patients who receive PCC less than 90 days before dying have their consultations inpatient while hospitalized,[36] limiting the time palliative care teams have to refer patients to services that enhance their quality of life.[35] Despite the benefits of having

early PCC[37,53,54] and GOC[1,55] conversations, little is known about risk factor profiles associated with the timing of these conversations in hospital settings where late conversations are more likely to occur.

The main aim of this study is to identify risk factor profiles associated with patients receiving palliative care consultations for GOC (hereafter called "PCC") 0-14 days before death ("PCC close to death"), 15-60 days before death ("moderately-timed PCC"), and more than 60 days before death ("early PCC").

The timing categories are based on Medicare hospice data, which shows 41% of patients on hospice received 0-14 days of care (28% received seven or fewer days of care, presumably in the last week of life), 26% received 15-60 days of care, and 33% received more than 60 days of hospice care.[45] Hospice care is associated with family perceptions of excellent quality EOL care and greater concordance between patient wishes and EOL care, with the highest quality EOL outcomes associated with patients receiving hospice for more than 30 days.[46] Evidence suggests efforts to decrease ICU admissions near EOL, decrease hospital deaths, and increase earlier hospice enrollment may improve the quality of EOL care.[5] Earlier PCC also allows for more opportunities to discuss treatment decisions and advance care planning,[35] topics in PCC that are associated with reduced hospitalizations near death and increased use of hospice.[54] Better understanding risk factors associated with PCC timing may help clinicians initiate these discussions earlier with patients at risk for having late conversations and enable patients to make decisions that result in high quality EOL care consistent with preferences.

To further understand associations between PCC timing and other outcomes, the secondary aims of this study are to describe discharge to hospice from index admission, presence of do-not-resuscitate (DNR) documentation during index admission, whether patients changed their GOC during index admission, and median EOL acute care costs (defined as direct acute care costs incurred in the health system during and following index hospital admission to

the point of death). Index admission is defined as the hospitalization in which PCC first occurred during the study period (**Appendix A**).[16]

Methods

Study Design

This secondary analysis was designed to identify risk factor profiles associated with the timing of PCC before death (0-14 days, 15-60 days, and greater than 60 days before death) among patients who received inpatient PCC at an academic medical center. Supplementary data from the medical center's electronic record database (Medicaid status and days between PCC and patient death) was matched to unique patient identifiers.

Dataset

Setting. Our analysis used data from a study conducted at a 776-bed, urban, academic medical center in the Northeast region.[16] The medical center serves a socioeconomically and racially diverse area of patients, composed of African Americans (46%), Whites (36%), Asians (9%), and Hispanics (6%).[56] In addition, the medical center receives a significant number of patients transferred from other hospitals in the region, including hospitals that serve predominantly White patients from areas with higher median incomes and education levels. The palliative care team at this medical center is well-established and predominantly operates as a consultation service. The team includes physicians, advance practice nurses, registered nurses, social workers, a pharmacist, and a chaplain.[16] Two-thirds of the team's consultations involve GOC discussions.[16]

Data. The dataset includes demographic, clinical, and financial cost information tied to each patient's healthcare utilization in the medical center during the study period (July 1, 2014 to October 31, 2016). The medical center's palliative care registry was used to identify all patients who received PCC specifically to discuss GOC during the study period. Consultations about pain or symptom management, psychosocial or spiritual distress, or transition planning that did not involve GOC discussion were excluded.

Sample. Our study included patients 18 and over who were admitted to the medical center between July 1, 2014 and October 31, 2016 (the study period), received PCC, and died during the study period. Patients were included if they died in the hospital system while on hospice or not on hospice, died outside the hospital system while on hospice, or died outside the hospital system not on hospice but had been seen by a provider affiliated with the medical center who updated the patient's medical record to reflect their death. Patients who were admitted for childbirth or rehabilitation were excluded, as were patients who died in community hospitals whose deaths were not updated in the medical center's records.

Data privacy and security. This study was approved by the University of Pennsylvania's Institutional Review Board, which granted the current study an exempt status (45 CFR 46.104, category #4). The investigators followed University of Pennsylvania procedures for ensuring patient data privacy and security. Prior to the transfer of data, all patient data was de-identified to ensure privacy and compliancy with the Health Insurance Portability and Accountability Act (HIPAA). Without sharing dates of initial PCC or dates of patients' deaths, the health system's director of analytics provided the number of days between initial PCC and patient death, ensuring patient privacy while allowing analysis to be unaffected by blinding. Age was provided in categorical groups to further protect patient identity. De-identified data was transferred through SecureShare, an internet-based application for securely exchanging files, and saved to a secure, encrypted folder on the University of Pennsylvania School of Nursing's firewall-protected network drive. Accessing the folder and the network drive requires two-step authentication. The network drive that contained the data is routinely monitored for system and security breaches. Only study investigators and approved personnel, had access to the de-identified study data.

Measures

Timing of palliative care consultations for goals-of-care. The primary outcome of interest is time between a patient's first inpatient PCC during the study period and patient death, categorized into three non-overlapping levels of data: PCC close to death, defined as 0-14 days

before death; moderately-timed PCC, defined as 15-60 days before death; and early PCC defined as more than 60 days before death. The date of first PCC during the study period was used to calculate days between first PCC and patient death (**Appendix A**). Although the literature suggests early palliative care referral may be defined as more than 90 days before death,[36] consultations occurring in that timeframe predominantly occur in outpatient settings.[36] Because this study focuses on GOC conversations occurring during inpatient hospitalization, the time parameters are shorter and were defined with other inpatient GOC studies in mind.[15,57]

Risk factors for profiles associated with the timing of PCC. Correlates included sociodemographic data such as age, gender, self-reported race/ethnicity, and Medicaid status; and clinical variables such as primary diagnosis at the time of index hospitalization discharge based on diagnosis-related group (DRG), All-patient refined DRG (APR-DRG) severity of illness (the extent of physiologic decomposition, determined at index hospitalization discharge), APR-DRG risk of mortality (the likelihood a patient will die, determined at index hospitalization discharge), whether a patient had any ICU care during the index admission, whether a patient had ICU care for more than six days during the index admission (to indicate high acuity), whether a patient was visited by an Oncology team during the index admission, source of referral to palliative care (e.g., Oncology), and acute care utilization in the 30 days before index admission (**Table 4.1**).

APR-DRG severity of illness and APR-DRG risk of mortality are assigned to a patient based on the diagnoses and procedures coded for billing during the hospitalization, and have four subcategories (minor, moderate, major, extreme) that are assigned by health system software designed to assess patient risk and resource allocation.[16,58,59] These measures take into account a patient's comorbidities and the stage and interaction of those diseases.[59] High scores are characterized by multiple serious illnesses and interaction among those illnesses, and are a reliable proxy for comorbidities.[60]

Descriptive variables associated with PCC timing. Discharge to hospice from index admission, DNR documentation during index admission, whether patients changed GOC during index admission, and EOL acute care costs (direct acute care costs incurred in the health system during and following index hospital admission to the point of death) are described (**Table 4.1**).

Statistical Methods

Descriptive statistics and measures of central tendency were used to characterize the variables and describe the sample based on timing of PCC before death (SAS v. 9.4, SAS Institute Inc., Cary, NC) (**Table 4.1**). Chi-squared tests were performed to examine associations between categorical variables. Kruskal-Wallis tests and analysis of variance (ANOVA) tests were performed for the distributions of continuous measures by PCC timing, as appropriate. There were minimal missing data in the dataset. Specialist referral data was missing for one patient. This patient was included in the study. (In the parent study, 0.4% of patients were excluded due to missing data.)

To inform development of the classification and regression tree (CART) model, an adjusted multinomial logistic regression model was built using all available, clinically meaningful independent variables (Stata v. 15, StataCorp, College Station, TX) (**Table 4.2**). Odds ratios were calculated across variables using early PCC as the reference group. Classification and regression tree modeling was then applied with SAS JMP software using all clinically meaningful variables, regardless of significance demonstrated in the multinomial logistic regression model (**Figure 4.1**). Risk of mortality is known to be a strong correlate of the PCC timing because it increases as a patient nears death.[61] To better understand the interaction of other variables, risk of mortality was excluded from the model. The CART model shows how independent variables, or risk factors, interact to create associations with the outcome of PCC timing.[62]

For CART modeling, the dataset was divided into training (N = 571), validation (N = 285), and test (N = 285) sets. In training the decision tree, CART analysis software recursively divided the training data one variable at a time to generate a series of splits that best identified the

outcome of PCC timing.[63] CART software chooses where to split variables based on where the division most accurately homogenizes the outcome variable while minimizing the model's misclassification rate, a process that results in subgroups more homogenous in the outcome of PCC timing than the original sample.[62,64] Specifically, splitting occurred when the decrease in entropy was less than 9.5. We then selected the tree with the most clinically meaningful patient profiles. The test set was used to evaluate performance of the decision tree. Traditional statistical power analyses do not apply to CART modeling,[65,66] but our sample was sufficient for running complex interactions because it was greater than the minimum 100 participants that is recommended.[66]

Results

Timing of PCC. The sample included 1,141 patients who received inpatient PCC prior to dying during the study period. Over half of patients received PCC 0-14 days before death (53.6%, n = 612); 25.6% received PCC 15-60 days before death (n = 292); and 20.8% received PCC more than 60 days before death (n = 237). Overall, patients had PCC a median of 13 days before death. Patients in the early PCC group received PCC a median of 135 days before death, patients who had PCC 15-60 days before death had it a median of 28 days before death, and patients in the PCC group close to death received PCC a median of 5 days before death ($P < 0.0001$). Over half (54%) of patients in our sample received PCC within two weeks of dying, 26% received PCC 15-60 days before death, and only 21% received PCC more than 60 days before death.

Correlates of the timing of PCC before death. **Table 4.1** presents the distribution of potential risk factor variables based on the timing of PCC before death. Variance Inflation Factor was less than three for all variables, indicating no evidence of multicollinearity among variables. Results of the adjusted multinomial logistic regression (**Table 4.2**) were limited, suggesting other variables not measured in this study may be associated with the timing of PCC before death. Small sample sizes within groups may also have contributed to this finding. There were no statistically significant differences among the three timing groups overall, but some differences

were significant between groups. For example, compared to patients over age 75, patients aged 56-60 were found to be almost two times more likely to have consults close to death than early (OR = 1.94, 95% Confidence Interval 1.09, 3.47; P = 0.03), with no significant difference for moderately-timed PCC relative to early. Compared to patients with cancer, patients in "other" diagnoses category were less likely to receive a moderately-timed consult than early consult (OR = 0.47, 95% Confidence Interval 0.22, 0.10; P = 0.049) and, although not significant, less likely to have PCC close to death (OR = 0.53, 95% Confidence Interval 0.28, 1.01; P = 0.052) compared to early. Patients with "Other" category had primary diagnoses such as skin conditions and ulcers, musculoskeletal conditions, psychiatric disorders, traumatic injuries, or postoperative or procedure-related conditions. These conditions were combined into the "Other" category due to smaller sample sizes. Finally, compared to referrals from Oncology specialists, patients referred to PCC by General Medicine/Hospitalists were two times more likely to have consults close to death (OR = 2.02, 95% Confidence Interval 1.16, 3.53; P = 0.01), with no significant difference for moderately-timed PCC compared to early.

Decision tree model identifies profiles of patients associated with receiving PCC close to death. As shown in **Table 4.3**, the CART model had 54.7% accuracy identifying the PCC timing outcome (CI 48.8%, 60.6%), which was similar to the predictive error in the test data (53.7%). The overall identification accuracy did not improve significantly, likely because the model was only able to accurately identify patients who received PCC close to death (model sensitivity for PCC close to death was 88.2%). The model's specificity for PCC close to death was 32.6%, which indicates the model less accurately identified patients who did not have PCC 0-14 days before death. Although the model demonstrated poor ability to identify patients who had early PCC or moderately-timed PCC (sensitivity 1.7% and 27.4%, respectively), the model effectively identified which patients did *not* receive early or moderately-timed PCC (specificity 99.1% and 82.1%, respectively)—timing that is preferable to PCC close to death. In short, the model was not effective at identifying which patients received moderately-timed (n = 147) or early PCC (n = 118), but it was effective at identifying which patients received PCC close to death (n = 306) and which

patients did not receive early or moderately-timed PCC. Smaller sample sizes, particularly for early and moderately-timed PCC groups, may have contributed to these findings.

Risk factor profiles associated with patients likely to receive PCC close to death. **Figure 4.1** illustrates the CART model's identification of patients most likely to receive PCC 0-14 days before death compared to moderately-timed and early PCC. In the model's depiction of complex interactions associated with PCC timing profiles, severity of illness was found to be the most important variable, followed by ICU use, age, primary diagnosis, race/ethnicity, use of Oncology services, and hospitalization 30 days prior to index admission. Severity of illness was highly associated with PCC timing: 64% of patients with extreme illness received PCC close to death. Only 13% of patients with extreme illness and 35% of patients with less than extreme severity of illness received PCC more than 60 days before death, indicating opportunities to discuss GOC earlier with patients. ICU use during index admission further increased probability of association with PCC timing. ICU patients with extreme illness severity were more likely to receive PCC close to death (64%). Although representing a lower probability, a staggering 50% of ICU patients with less than extreme severity of illness also received PCC within 14 days of death. Patients with extreme illness severity who were in the ICU and were Hispanic, "Other" racial/ethnic minority (American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, or "Other" race/ethnicity), or did not disclose their race/ethnicity were more likely to receive PCC close to death (85%); age under 46 or older than 75 further increased this probability (98%). Non-ICU patients with extreme severity of illness, no hospital admission in the previous 30 days, and a primary diagnosis of cancer, other cardiovascular disorders, endocrine disorders, GI disorders, gynecological or urological disorders, blood disorders, infectious disease, sepsis, musculoskeletal disorders, or neurologic disorders had a 58% probability of PCC close to death—a probability (96%) that dramatically increased if the patient was also age < 40 or > 75.

On the other hand, patients with non-extreme illness severity who were not in the ICU were less likely to receive PCC close to death (24%). Non-ICU patients with extreme illness severity with conditions other than heart failure, respiratory disorder, or "Other" condition who did

not receive Oncology care during index admission but had been admitted to the hospital 30 days prior also demonstrated low probability for PCC close to death (19%). Finally, non-ICU patients with extreme severity of illness who had heart failure, a respiratory disorder, or "Other" diagnosis had the lowest probability of PCC close to death (17%) and high probability for early PCC (80%). It is unknown if this is a case of reverse causation or if other factors are involved.

Findings of the secondary aims. During index admission, patients spent a median 11 days hospitalized (IQR 6-22 days, P < 0.0001), 3 days in the ICU (IQR 0-11 days, P < 0.0001), and incurred median direct acute care costs of $26,005 (IQR $12,908-$59,889; P = 0.18; and mean costs of $51,000, SD $93,302; P = 0.02). Index admission utilization and costs were generally greatest among patients who received PCC 0-14 days before death. PCC groups differed in age (P = 0.04), race/ethnicity (P = 0.02), primary diagnosis (P = 0.006), severity of illness (P < 0.0001), risk of mortality (P < 0.0001), ICU care during index admission (P < 0.0001), ICU care greater than 6 days during index admission (P < 0.0001), and whether they had been visited by the Oncology team during their index admission (P = 0.03). About 80% of PCC patients changed their GOC during PCC, with rates increasing the closer a patient was to death (P < 0.0001). Do-not-resuscitate (DNR) documentation also increased the closer a patient was to death (early PCC 26%, PCC 15-60 days 59%, PCC close to death 86%, P < 0.0001), with 67% of the total sample having resuscitation wishes documented during index admission. It is unknown if DNR documentation occurred before or after PCC.

Discussion

The CART model effectively identified factors associated with PCC 0-14 days before death, making it a useful tool for identifying vulnerable patients at risk of PCC close to death, and provided insights into patient populations likely to receive PCC 15-60 and > 60 days before death. In addition, the model effectively identified which patients did not receive early or moderately-timed PCC, which enables clinicians to identify and target patients who are not getting more optimally-timed, beneficial consultations, and develop interventions that better support such patients' needs. The model was not able to accurately identify which patients received early or

moderately-timed PCC, possibly because relatively few patients received early PCC and because already small sample sizes for these groups diminished in the context of variable interactions. It is also possible variables not included in our model may have improved the model's ability to identify patients likely to receive moderately-timed or early PCC. Given that more than half the patients in the sample died within 14 days of receiving PCC and only one-fifth received PCC more than 60 days before death, this study illuminates a critical need for clinicians to engage patients with serious illness in PCC discussions about GOC earlier in the illness trajectory. Patients in our study received PCC a median 13 days before death, which is less than the national median length of hospice care (24 days)[67] and cancer studies that show median times ranging from 16-33 days between PCC and death.[15,43,44]

Among complex interactions identified by CART modeling, ICU utilization was found to be the second greatest contributor to risk factor profiles associated with PCC timing. Intensive care during index admission for patients with extreme severity of illness contributed to a 67% probability of PCC close to death (and 50% probability of PCC close to death for all other ICU patients), suggesting the importance of coordinating PCC for patients in the ICU regardless of illness severity. This finding is consistent with evidence-based recommendations to involve PCC when caring for patients in the ICU.[28,68] One recent study found patients in the neuro-ICU who received PCC were more likely to change GOC to less invasive care, receive fewer procedures in the last 48 hours of life, and receive better symptom management.[69] Another study found involving PCC in the ICU increased advance care planning and decreased use of aggressive interventions.[70] Consulting palliative care earlier in the ICU stay gives patients and families more time to benefit from GOC discussions and the improvements in symptom and care management that follow. Because all ICU patients can benefit from PCC, research into systematic processes for involving PCC early in the ICU admission, such as those developed using evidence-based triggers and machine learning, are recommended.[68,71,72] Early evidence suggest systematic processes increase PCC in the ICU,[71] possibly reducing disparities that result from referral-driven care.

A more systematic process for involving PCC in the care of patients with serious illness may also help reduce racial/ethnic disparities in EOL care. It is unknown why ICU patients who self-identified as Hispanic or other racial/ethnic minority demonstrated such a high probability for receiving PCC close to death. Hispanics and other racial/ethnic minorities endure disparities in access to care and experiences throughout the care continuum that may influence when they first receive PCC.[73-79] For example, providers are less likely to have EOL discussions[55] and less likely to discuss prognosis[80] with Hispanics and other racial/ethnic minorities, possibly influencing their health literacy and receptivity to PCC.[76] Other factors such as religiosity, family dynamics, and socio-cultural preferences may also contribute to PCC timing.[76,79,81] More research is needed to better understand barriers to earlier PCC with severely ill Hispanics and other racial/ethnic minorities, and how clinicians can overcome such barriers to better support racial/ethnic minorities with serious illness.[73-75] Improved communication and earlier involvement with PCC may help reduce the disparities in EOL care and costs documented among Hispanic patients and other minorities.[17,73,81-83]

The model found only 17% probability that non-ICU patients with extreme severity of illness who were admitted for heart failure, a respiratory condition, or a condition not otherwise listed (e.g., pressure ulcers, musculoskeletal conditions) had PCC close to death. According to CART, these patients had 80% probability of having early PCC. Patients with advanced heart failure and respiratory disorders such as chronic obstructive pulmonary disease have different illness trajectories than, for example, patients with cancer. The patterns of organ failure associated with conditions like heart failure cause patients to be hospitalized during acute crises from which they may recover. Patients who recover after receiving PCC during a disease exacerbation may partially compose the early PCC group. Research is needed to better understand which patients receive PCC early and why.

Over half the patients who had PCC more than 60 days before death changed their GOC during PCC, suggesting the relevance and appropriateness of earlier conversations. The proportion of patients who changed their GOC during PCC increased the closer a patient was to

death, as did DNR documentation. Had patients engaged in these discussions earlier, they may have chosen to change their care goals earlier and may have benefitted from greater time receiving care consistent with their preferences. Health systems seeking to manage costs may also benefit from offering patients earlier PCC. Despite having significantly more days to accrue costs before death, as measured in our study, patients with earlier PCC had only $8,993 greater median acute care EOL costs than patients who had PCC within 14 days of dying. Other evidence suggests that early PCC appears to mediate the increase of inpatient costs toward EOL observed among patients who receive late PCC,[36] but more research is needed to understand the monetary effect each day before death PCC has on EOL acute care costs.

This medical center treats a high number of severely ill patients transferred from other hospitals within the region, which may have contributed to the majority of patients receiving PCC close to death. Although timing improvements can be made in acute care settings using systematic triggers for inpatient PCC among eligible patients,[71,72,84-86] poor access to PCC in the community likely contributes to late timing. Increased access to community-based palliative care models would improve the time between PCC and death, enable patients to benefit from palliative care longer,[36,87] and help meet patient needs throughout the care experience and not just during inpatient hospitalizations.[88,89]

Limitations

This study is limited in a few ways. First, given the secondary nature of the study, a limited number of variables were available to assess. We were unable to assess other relevant confounders such as socioeconomic variables (e.g., health literacy, income, or education level), or religious and cultural beliefs. Due to the observational nature of the study, some unavailable variables may be salient in risk factor profiles associated with the timing of PCC or be important confounding factors, influencing results. Fortunately, the study was able to assess Medicaid use, which can be considered a proxy for socioeconomic variables because its eligibility is based on income. In addition, the index PCC may have occurred before some of the correlates, such as

ICU admission or the assignment of severity of illness or risk of mortality, making conclusions about chronology unfeasible but still resulting in relevant insights.

Second, our study does not include patients whose date of death is not recorded in the health system database. Patients who received PCC but whose death information is not available may have had shorter or longer durations between consultation and death. As such, the variables we measured may be distributed differently across the three groups and may be associated with timing differently. Given that 64% of the patients who received PCC in the parent study died during the study period, and that not all patients are likely to have died during the study period, our sample may include most patients who died during the study period. Unfortunately, we were unable to differentiate between patients who died within the health system and those who died outside the health system but whose death information was updated by providers affiliated with the medical center (e.g., specialty physicians in an outpatient setting). We were unable to assess any differences in demographic or clinical factors between patients whose deaths occurred in-system versus those whose deaths occurred outside the system. If there were differences in these sub-populations, we were unable to account for them in our analysis.

Finally, our study examined a single academic medical center with high acuity and a well-established palliative care team located in an area with significant racial, ethnic, and socioeconomic diversity. As such, the medical center may not represent all hospitals caring for patients with serious illnesses, possibly limiting generalizability of results. Willingness to engage in GOC/EOL conversations and referral patterns to PCC may differ in other systems. Despite these limitations, our study results increase understanding of risk factor profiles associated with the timing of inpatient PCC, including how race/ethnicity are associated with the timing of GOC discussion.

Ethical Considerations

Given PCC's association with less aggressive care and higher quality of life, and its role in patient and family informed decision-making, identifying patients at risk for late consultation is

an ethical priority. All patients should be given time to adequately understand prognosis and consider care options, but our research shows the majority of patients receive consultation within two weeks of dying and that disparities exist. The interaction of illness severity, ICU care, and race/ethnicity suggests a need for more culturally effective care of seriously ill patients from diverse backgrounds and a need for a more systematic process that integrates PCC across the care continuum. Patients and families cannot reap the benefits of earlier palliative care if policies and payment schemes do not support palliative care delivery in the community. New policies, payment models, and innovative workforce models involving trained nurses and primary care providers are needed to ethically and effectively deliver palliative care earlier to patients with serious illness.

Conclusions

The majority of patients with serious illness who had PCC before dying did so within two weeks of death, which may not be enough time to make decisions that result in the kind of death and dying experience patients and families desire. A complex set of factors was associated with PCC timing. Regardless of illness severity, ICU care is associated with patients receiving PCC close to death, suggesting the need for systematic PCC across ICU patient populations. Racial/ethnic disparities persist in the timing of PCC for extremely sick Hispanic and other racial/ethnic minorities, making it an ethical priority to provide earlier, culturally-effective care and communication to racial/ethnic minority patients. Timely communication of patient goals, values, and EOL preferences should start in the community before inpatient hospitalization when late PCC is likely to occur. Innovative care and payment models, policies, and workforce solutions are needed to support earlier integration of palliative care in acute and community settings.

Tables

Table 4.1 Description of Study Population

		Total	PCC 0-14 days before death	PCC 15-60 days before death	PCC > 60 days before death	P value
		N = 1,141	**N = 612** (53.6%)	**N = 292** (25.6%)	**N = 237** (20.8%)	
Median number of days between PCC and death (IQR)		13.0 (4.0-46.0)	5.0 (2.0-8.0)	28.0 (20.0-39.5)	135.0 (89.0-281.0)	-
Age (years)	18-39	6.6%	6.4%	6.8%	6.8%	**0.037**
	40-45	3.7%	3.6%	4.4%	3.0%	
	46-50	3.9%	3.4%	5.1%	3.8%	
	51-55	9.1%	7.8%	9.6%	11.8%	
	56-60	12.9%	13.2%	13.0%	11.8%	
	61-65	13.6%	13.4%	14.4%	13.1%	
	66-70	16.1%	15.0%	20.2%	13.9%	
	71-75	13.1%	12.6%	14.7%	12.2%	
	>75	21.0%	24.5%	11.6%	23.6%	
Gender	Male	46.6%	55.2%	51.0%	51.5%	0.40
	Female	53.4%	44.8%	49.0%	48.5%	
Self-identified Race/Ethnicity	African American/Black	25.0%	22.4%	28.4%	27.4%	**0.02**
	Asian	3.8%	3.3%	3.8%	5.1%	
	Hispanic	2.2%	2.1%	2.1%	2.5%	
	White	59.3%	60.0%	59.6%	57.4%	
	Other	3.2%	3.1%	2.7%	4.2%	
	Unknown/Chose not to disclose	6.5%	9.2%	3.4%	3.4%	
Medicaid	Yes	10.3%	9.3%	10.3%	13.1%	0.27

		Total	PCC 0-14 days before death	PCC 15-60 days before death	PCC > 60 days before death	P value
		N = 1,141	N = 612 (53.6%)	N = 292 (25.6%)	N = 237 (20.8%)	
	No	89.7%	90.7%	89.7%	86.9%	
Primary Diagnosis	Cancer	33.2%	31.2%	37.0%	33.8%	**0.006**
	Cardiovascular disorder / Heart failure	20.3%	22.9%	16.8%	18.1%	
	Endocrine disorder	1.9%	2.0%	2.7%	0.8%	
	GI disorder	7.1%	5.2%	9.2%	9.3%	
	Gynecologic or urologic disorder	2.8%	2.8%	3.8%	1.7%	
	Infectious disease and Sepsis	14.0%	15.4%	11.6%	13.5%	
	Neurologic disorder	6.9%	8.3%	6.5%	3.8%	
	Respiratory disorder	7.1%	7.0%	6.5%	8.0%	
	Other	6.6%	5.2%	5.8%	11.0%	
APR-DRG Severity of Illness	Minor	1.6%	1.1%	1.7%	2.5%	**<0.0001**
	Moderate	5.5%	3.6%	6.2%	9.7%	
	Major	28.1%	18.6%	34.6%	44.7%	
	Extreme	64.8%	76.6%	57.5%	43.0%	
APR-DRG Risk of Mortality	Minor	3.0%	1.8%	4.5%	4.2%	**<0.0001**
	Moderate	8.8%	4.1%	11.3%	17.7%	
	Major	29.8%	22.7%	34.2%	42.6%	
	Extreme	58.5%	71.4%	50.0%	35.4%	
Acute care hospitalization 30 days prior to index hospitalization	Yes	23.0%	21.6%	27.4%	21.5%	0.124
	No	77.0%	78.4%	72.6%	78.5%	
	Yes	67.0%	77.6%	55.1%	54.4%	**<0.0001**

		Total	PCC 0-14 days before death	PCC 15-60 days before death	PCC > 60 days before death	P value
		N = 1,141	**N = 612** (53.6%)	**N = 292** (25.6%)	**N = 237** (20.8%)	
ICU care during index admission	No	33.0%	22.4%	44.9%	45.6%	
ICU care > 6 days during index admission	Yes	40.3%	46.1%	37.3%	29.1%	**<0.0001**
	No	59.7%	53.9%	62.7%	70.9%	
Specialist who referred patient to Palliative Care for PCC (one patient had a missing value)	Cardiology	10.8%	10.5%	13.1%	8.9%	0.35
	Gynecology/Oncology	3.9%	4.4%	4.1%	2.1%	
	General Medicine/Hospitalist	13.3%	13.6%	14.8%	11.0%	
	Neurology	7.3%	6.2%	7.6%	9.7%	
	Oncology	34.6%	34.0%	31.3%	40.5%	
	Pulmonary	9.8%	10.1%	10.3%	8.4%	
	Surgery	17.9%	19.1%	16.8%	16.0%	
	Other	2.4%	2.1%	2.1%	3.4%	
Visited by Oncology during index admission	Yes	30.0%	27.3%	36.0%	29.5%	**0.03**
	No	70%	72.7%	64%	70.5%	
Median days spent hospitalized during index admission (IQR)		11.0 (6-22)	9.0 (5-17)	16.0 (7-27.5)	11.0 (7-24)	**<0.0001**
Median ICU days during index admission (IQR)		3.0 (0-11)	5.0 (1-11)	1.5 (0-13)	1.0 (0-7)	**<0.0001**
Median direct acute care costs during index admission (IQR)		$26,005 ($12,908-$59,889)	$28,330 ($13,635-$58,476)	$27,542 ($11,572-$75,175)	$21,397 ($12,357-$47,064)	0.18
Median EOL direct acute care costs *(index admission plus future acute care costs in health system until death)* (IQR)		$31,082 ($14,880-$67,035)	$28,333 ($14,200-$58,476)	$34,113 ($14,484-$77,510)	$37,326 ($18,461-$89,057)	**0.0001**

		Total	PCC 0-14 days before death	PCC 15-60 days before death	PCC > 60 days before death	P value
		N = 1,141	N = 612 (53.6%)	N = 292 (25.6%)	N = 237 (20.8%)	
Changed goals-of-care during PCC index admission (% yes)		79.7%	93.0%	75.7%	50.2%	**<0.0001**
DNR documented index admission	Yes	66.9%	86.3%	59.2%	26.2%	**<0.0001**
	No	33.1%	13.7%	40.8%	73.8%	
Discharged to hospice[1]	Yes	27.1%	31%	32.5%	10.1%	**<0.0001**
	No	72.9%	69%	67.5%	89.9%	

[1]From index admission including PCC. Chi-squared test of association was used to test differences among percentage variables. Kruskal-Wallis tests and analysis of variance (ANOVA) were performed for the distributions of continuous measures by PCC timing as appropriate.

Table 4.2 Adjusted Multinomial Logistic Regression Model Showing Variables Associated with PCC Timing before Death

Variable		PCC 0-14 days vs. > 60 days (ref)		PCC 15-60 days vs. > 60 days (ref)		Overall P value
		Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value	
Age in years (**reference:** >75)	18-39	1.896 (0.849, 4.233)	.1184	2.308 (0.952, 5.600)	.0643	.5773
	40-45	1.711 (0.646, 4.532)	.2801	2.152 (0.731, 6.335)	.1642	
	46-50	1.071 (0.427, 2.691)	.8832	2.294 (0.883, 5.958)	.0881	
	51-55	1.106 (0.596, 2.050)	.7498	1.380 (0.689, 2.766)	.3634	
	56-60	1.943 (1.089, 3.468)	**.0245**	1.835 (0.945, 3.565)	.0730	
	61-65	1.25 (0.729, 2.142)	.4179	1.31 (0.702, 2.442)	.3961	
	66-70	0.945 (0.577, 1.549)	.8237	1.104 (0.623, 1.955)	.7346	
	71-75	1.142 (0.666, 1.96)	.6291	1.262 (0.677, 2.353)	.4634	
Gender (**reference:** Male)	Female	0.837 (0.609, 1.152)	.2754	1.052 (0.733, 1.509)	.7843	.2585
Self-Identified Race/Ethnicity (**reference:** White)	African American/Black	1.091 (0.744, 1.601)	.6545	1.186 (0.769, 1.831)	.4402	.3485
	Other (includes Asian, Hispanic, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, and "Other" race/ethnicity) *	0.785 (0.452, 1.364)	.3903	1.209 (0.666, 2.196)	.5326	
	Unknown/Chose not to disclose	2.022 (0.932, 4.386)	.0747	1.838 (0.775, 4.359)	.1669	
Medicaid (**reference:** No)	Yes	0.851 (0.485, 1.492)	.5728	0.853 (0.459, 1.587)	.6164	.8395
Primary Diagnosis (**reference:** Cancer)	Cardiovascular disorder/Heart Failure	0.718 (0.44, 1.171)	.1845	0.752 (0.434, 1.303)	.3090	.4431
	Endocrine disorder	1.763 (0.472, 6.581)	.3988	1.061 (0.235, 4.788)	.9388	
	GI disorder	0.643 (0.34, 1.215)	.1742	0.728 (0.365, 1.451)	.3667	

Variable		PCC 0-14 days vs. > 60 days (ref)		PCC 15-60 days vs. > 60 days (ref)		Overall P value
		Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value	
	Gynecologic/Urologic	0.728 (0.27, 1.964)	.5301	1.132 (0.4, 3.204)	.8152	
	Infectious disease/Sepsis	0.906 (0.542, 1.514)	.7059	0.594 (0.323, 1.093)	.0940	
	Neurologic disorder	0.955 (0.479, 1.903)	.8949	0.997 (0.46, 2.159)	.9932	
	Respiratory disorder	1.037 (0.535, 2.011)	.9134	0.608 (0.276, 1.339)	.2170	
	Other	0.534 (0.284, 1.006)	.0522	0.472 (0.224, 0.995)	**.0485**	
APR-DRG Severity of Illness (**reference:** Minor)	Moderate	0.54 (0.115, 2.524)	.4334	0.619 (0.119, 3.228)	.5694	.9116
	Major	0.762 (0.157, 3.69)	.7356	1.061 (0.197, 5.722	.9448	
	Extreme	0.721 (0.143, 3.633)	.6920	0.924 (0.163, 5.232)	.9290	
APR-DRG Risk of Mortality (**reference:** Minor)	Moderate	0.586 (0.175, 1.965)	.3870	0.486 (0.136, 1.736)	.2669	.2186
	Major	0.627 (0.181, 2.17)	.4609	0.392 (0.105, 1.46)	.1626	
	Extreme	1.084 (0.296, 3.974)	.9035	0.487 (0.122, 1.945)	.3083	
Acute care hospitalization 30 days prior to index hospitalization (**reference:** No)	Yes	1.246 (0.841, 1.845)	.2726	1.166 (0.753, 1.806)	.4908	.5474
ICU care during index admission (**reference:** No)	Yes	1.122 (0.731, 1.723)	.5985	0.703 (0.431, 1.146)	.1577	.0741
ICU care > 6 days during index admission (**reference:** No)	Yes	0.988 (0.663, 1.472)	.9519	1.243 (0.777, 1.989)	.3643	.4782
Specialist who referred patient to Palliative	Cardiology	1.014 (0.603, 1.706)	.9588	0.865 (0.473, 1.58)	.6369	.2785
	Gynecology/Oncology	1.819 (0.703, 4.705)	.2172	2.1 (0.756, 5.834)	.1548	
	General Medicine/Hospitalist	2.023 (1.158, 3.533)	**.0133**	1.776 (0.956, 3.3)	.0692	

Variable		PCC 0-14 days vs. > 60 days (ref)		PCC 15-60 days vs. > 60 days (ref)		Overall P value
		Odds Ratio (95% CI)	P value	Odds Ratio (95% CI)	P value	
Care for PCC (**reference:** Oncology)	Neurology	0.684 (0.385, 1.214)	.1943	0.589 (0.298, 1.165)	.1282	
	Pulmonary	1.141 (0.652, 1.995)	.6439	1.096 (0.583, 2.063)	.7753	
	Surgery	1.41 (0.888, 2.239)	.1456	1.371 (0.817, 2.301)	.2326	
	Other	0.76 (0.296, 1.946)	.5669	0.521 (0.158, 1.721)	.2852	
Visited by Oncology service during index admission** (**reference**: No)	Yes	1.234 (0.831, 1.831)	.2968	1.382 (0.892, 2.142)	.1474	0.3471

***** Asian and Hispanic patients are in the "Other" race/ethnicity category of this model because they were not evenly distributed across PCC timing groups and their estimates could not be established when considered separately.

** Oncology service met with the patient as the patient's 1st or 2nd service during index hospitalization.

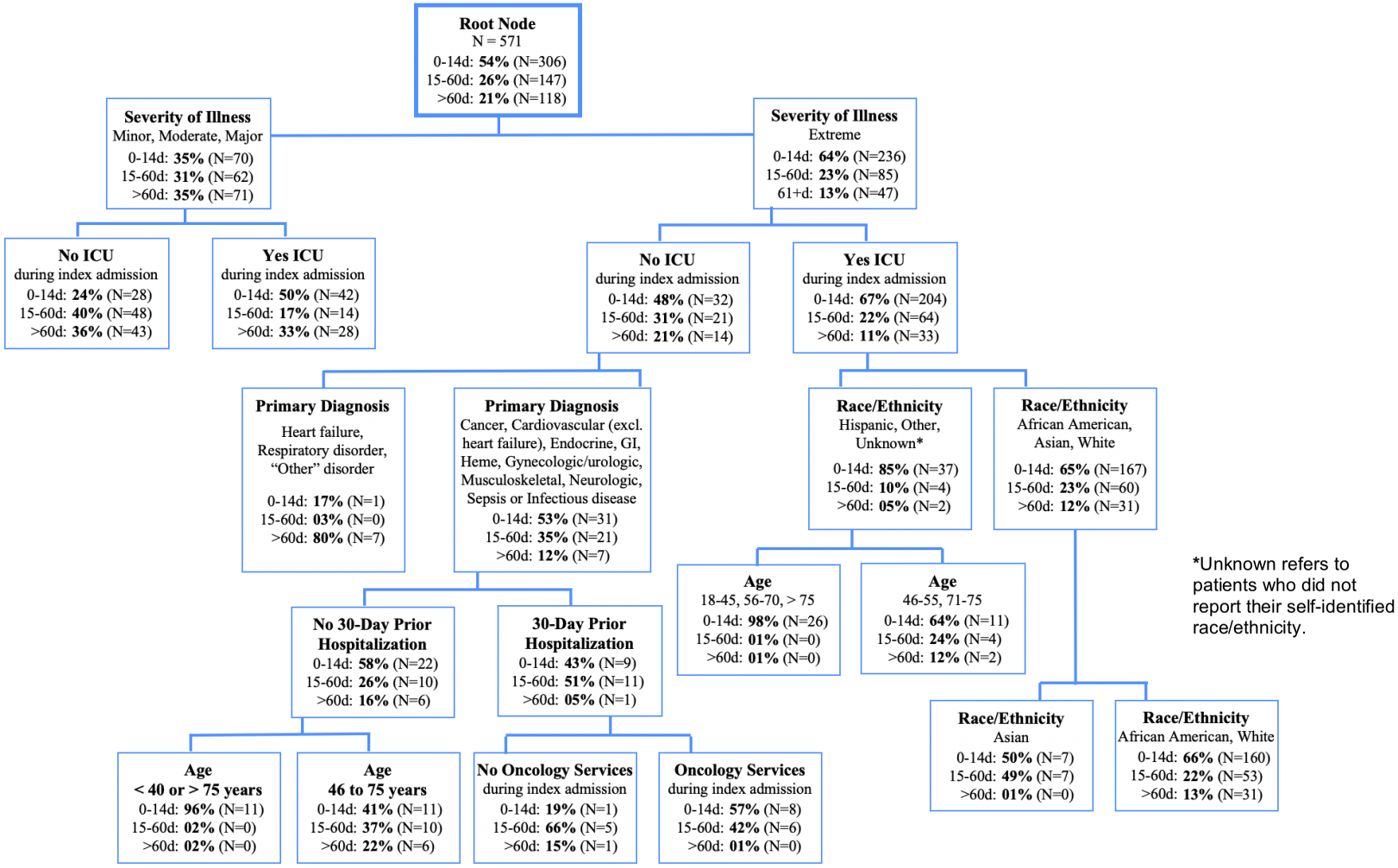
Table 4.3 Classification and Regression Tree (CART) model performance for identifying profiles associated with the timing of palliative care consultation for goals-of-care before death

Sample	Statistic	Value
PCC patients who died during the study period	Root node error	0.537
	Accuracy (95% Confidence Interval)	0.547 (0.488, 0.606)
	P-Value [Acc >NIR]	0.384
Patients with PCC 0-14 days before death	Sensitivity	0.882
	Specificity	0.326
	Positive predictive value	0.603
	Negative predictive value	0.705
Patients with PCC 15-60 days before death	Sensitivity	0.274
	Specificity	0.821
	Positive predictive value	0.345
	Negative predictive value	0.767
Patients with PCC > 60 days before death	Sensitivity	0.017
	Specificity	0.991
	Positive predictive value	0.333
	Negative predictive value	0.794

*The P-value represents the probability that model accuracy is higher than the no information rate (NIR). Sensitivity represents the proportion of patients correctly identified in the model as having had PCC in the associated timeframe. Specificity represents the proportion of patients that did not have PCC in the associated timeframe and were correctly identified in the model. Positive predictive value is the proportion of patients who actually received PCC in the associated timeframe out of all patients identified in the model as having received PCC in that timeframe. Negative predictive value is the proportion of patients who actually did not receive PCC in the associated timeframe out of all those identified in the model as having not received PCC in that timeframe.

ILLUSTRATIONS

Figure 4.1 Classification and Regression Tree showing risk factor profiles for the timing of PCC before death



*Unknown refers to patients who did not report their self-identified race/ethnicity.

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CHAPTER FIVE: DISCUSSION AND CONCLUSIONS

Introduction

The United States spends more money on patients in the last year of life than any country in the world.[1] This high spending does not necessarily reflect higher quality EOL care compared to other developed countries, but instead reflects greater use of intensive and acute care at EOL.[2-4] Aggressive EOL care is not only significantly more expensive than less aggressive care,[5] it is also associated with lower quality EOL care[6-8] and higher decision regret among families.[9,10] Evidence suggests most patients do not prefer aggressive EOL care.[11-15] This incongruity between care preferences and EOL practices may be mitigated by EOL discussions about care preferences led by trained professionals, including palliative care consultation (PCC) teams.

Patient-provider discussions about end-of-life (EOL) and goals-of-care (GOC), including those that occur during PCC, enable patients to ask important questions, express their understanding of the terminal nature of their illness, and communicate what is important to them as they near EOL. Understanding a patient's values, goals, and care preferences enables clinicians to provide care concordant with expressed desires,[16-18] allowing vulnerable patients to have more of the dying experience they want. These critical conversations are associated with less aggressive, less intensive care near EOL,[2,13,17,19-21] which in turn is associated with higher quality EOL care[6-8] and lower regret for EOL treatment decisions.[9,10] End-of-life and GOC discussions are also associated with lower acute care costs near death, with early evidence of savings ranging from $6,000 to $9,500 per patient.[2,21,22] Lower EOL costs are associated with better quality of death,[2] making the exploration of EOL costs and communication an ethical necessity. End-of-life discussions and PCC mutually benefit patients and health systems: patients who have these conversations appear to experience a higher quality dying experience more consistent with values and preferences, and health systems incur lower costs as a result.[2,23]

African Americans and other racial/ethnic minorities in the United States are less likely to have important EOL care planning discussions with their healthcare providers[24-30] and are more likely to receive intensive, life-prolonging EOL care compared to Whites.[24,31-36] They are also reported to have higher EOL costs,[31] which may contribute to a lower quality dying experience.[2] In its groundbreaking report (2015), *Dying in America,* the National Academy of Medicine called for more research into racial/ethnic disparities in EOL care,[37] but costs studies have been limited to date. In fact, evidence about EOL discussions, including those occurring during PCC, and future healthcare utilization and costs has been especially limited in the context of race/ethnicity and the timing of conversations.

Overall Goals

To fill gaps in the literature, this dissertation achieved the following goals: it explored associations among EOL discussions, healthcare utilization, place of death, and costs in persons with advanced cancer near EOL (Aim 1, Chapter 2); assessed future acute care costs and healthcare utilization following palliative care consultation to discuss GOC or EOL (hereafter called "PCC") among Whites and African Americans with serious illness who either did or did not have PCC (Aim 2a, Chapter 3); described acute care utilization, costs, and discharge to hospice among racial groups who received PCC (Aim 2b, Chapter 3); examined risk factor profiles for PCC 0-14 days before death ("PCC close to death"), 15-60 days before death ("moderately-timed PCC"), and greater than 60 days before death ("early PCC") among deceased persons with serious illness who had PCC prior to dying (Aim 3a, Chapter 4); and described EOL acute care costs, changes in GOC, DNR documentation, and discharge to hospice from a hospitalization with PCC among deceased patients (Aim 3b, Chapter 4). These objectives were achieved through a systematic review of the literature (Aim 1); a propensity-matched cohort study of secondary data from a large, urban, academic medical center (Aim 2); and multinomial logistic regression models and classification and regression tree analysis of decedents who received PCC from the same dataset (Aim 3).

The systematic review presented in Chapter 2 revealed significant variations in how researchers and clinicians define advance care planning (ACP) and EOL discussions, and in how they conceptualize and measure care outcomes. It also showed a gap in research exploring EOL discussions and acute care costs, which this dissertation sought to help fill. Chapter 3 identified a cost-savings of almost $9,000 per White patient associated with PCC and directional (yet not statistically significant) savings among African Americans with PCC, suggesting PCC is a cost-effective intervention, but that larger studies across multiple medical centers are needed to understand why PCC is not significantly associated with reductions in future costs among African Americans. Most notably, Chapter 3 also showed how PCC is associated with dramatic increases in hospice use among both African Americans and Whites with PCC. Chapter 3 also provided helpful cost and utilization data on underrepresented racial minority populations. Finally, Chapter 4 revealed risk factor profiles for PCC 0-14 days before death, 15-60 days before death, and greater than 60 days before death. Together, these results point to some of the many benefits of PCC, including opportunities to discuss and document care goals, enroll in hospice care or choose less aggressive treatment, and conserve hospital resources in ways that align with patient preferences. The results also suggest PCC may play different roles in acute care utilization decision-making among different racial/ethnic groups and that other unmeasured factors may contribute to PCC timing and effectiveness, highlighting the need for clinicians to adapt PCC to patient and family needs, and for PCC to be integrated in care earlier in the illness experience.

Major Findings

Chapter Two: End-of-Life Discussions and Advance Care Planning are Associated with Lower EOL Costs and Less Aggressive Healthcare in Persons with Cancer

High costs near the end-of-life (EOL) represent utilization of costly acute and life-prolonging care near death[5] and are associated with poor quality of death among patients.[2] High costs burden patients,[38-42] families,[43] and health systems responsible for providing cost-effective, high-quality care.[21] Importantly, costly aggressive care does not always align with patient goals and preferences.[10] As the second leading cause of death worldwide[44,45] and one of the most

expensive conditions to treat,[46] cancer uniquely challenges clinicians to provide evidence-based and cost-effective care aligned with patient preferences. Patient-provider discussions about care goals and EOL preferences are associated with less aggressive care near death[2,20,47,48] and lower costs,[49,50] making them a useful intervention for enabling health systems to improve concordance between care preferences and actual care delivered[51] and increasing quality of care[48] while managing resources.[21]

The systematic review found that among patients with advance-stage cancer, discussions involving ACP, EOL or GOC were associated with lower acute healthcare costs in the last 30 days of life (median $1,048 vs. $23,482; P < .001), but more cost research is needed. The review also found these discussions are associated with less utilization of costly acute and aggressive care near death and greater use of hospice care, which is associated with lower costs and higher quality care. Specifically, the review found EOL and care planning discussions were associated with lower likelihoods of acute care [Odds Ratios (OR) ranging 0.43 to 0.69], intensive care (ORs ranging 0.26 to 0.68), emergency department use, and chemotherapy near death (ORs 0.41, 0.57); shorter hospital length of stay; and greater use of hospice (ORs ranging 1.79 to 6.88) and odds for death outside the hospital. Furthermore, the review found that the timing of these conversations was important. Perhaps because patients and families had more time to understand prognosis and consider care options in light of patient values and goals, earlier conversations (30 or more days before death) were found to be more strongly associated with less aggressive care outcomes than later conversations.

Based on the review's findings, clinicians can conclude that EOL and care planning discussions are effective at helping patients achieve dying experiences that involve less aggressive care, and that these conversations should occur earlier in the care continuum for all cancer patients. Per this review, less aggressive care associated with EOL discussions also appears to be associated with significant cost savings, which also benefit health systems. However, cost data was very limited. More research is needed to understand the ways these

discussions are associated with EOL costs and what influences the timing of when patients receive these conversations.

Chapter Three: Palliative Care Consultation is Associated with Lower Costs for White Patients and Greater Hospice Utilization for African Americans, Whites, and Other Racial/Ethnic Minorities

Even though race does not predict EOL preferences,[52,53] African Americans and other racial/ethnic minorities are less likely than Whites to receive hospice care[54,55] and more likely to prefer and receive costly acute or aggressive care near death[24,31-36,56,57] and die in hospitals.[31] These differences in EOL acute care utilization result in significantly greater EOL costs for African Americans and other racial/ethnic minorities compared to Whites,[31] even after controlling for other factors.[58] Unfortunately, high EOL costs, which reflect greater utilization of acute and intensive care services, are associated with poorer quality of death.[2] Goals-of-care and EOL discussions with healthcare providers, such as those that occur during PCC, are associated with less aggressive EOL treatment[2,10,20,21,59-65] that is perceived to be higher quality[2,9,37,47] and significantly lower acute care costs following discussion, including across hospitalizations.[21,22] Unfortunately, African Americans and other racial/ethnic minorities are less likely than Whites to have important care planning and EOL discussions with their healthcare providers.[24-29] Early evidence, however, suggests race is not a factor in which patients receive PCC, making it a possible solution for helping to overcome racial disparities in EOL care. However, studies assessing associations between EOL or GOC discussion, or PCC, and costs have not analyzed cost outcomes by race.

In this study, the association between PCC and acute care costs across hospitalizations following discharge from an admission involving PCC was examined (Aim 2a). This secondary analysis of preexisting clinical and administrative data included 35,154 African American and White patients with serious illness who were hospitalized at an urban academic medical center. A portion of the patients received PCC (African Americans with PCC, N = 383; Whites with PCC, N = 814). Variables of age, gender, Medicaid status, primary diagnosis, All-patient refined diagnosis

related group (APR-DRG) Risk of Mortality, APR-DRG Severity of Illness, intensive care unit (ICU) care during index admission, ICU care greater than six days during index admission, Oncology services during index admission, acute care costs accumulated during the index admission to represent acute care utilization, acute care hospitalization in 30 days prior to index admission were used to match patients who received PCC and patients who didn't receive PCC for both racial groups, resulting in two separate race-based stratified propensity score models. For each model, patient data from the two propensity groups most likely to have received PCC were used to assess outcomes.

Stratified propensity score modeling for African American patients found African Americans who received PCC were less likely to incur "any future acute care cost" compared to African Americans who did not receive PCC (31.9% vs. 37.7%, P = 0.047), but differences in total future acute care costs were not statistically significant ($11,651 vs. $15,050, P = 0.09). Of great importance, African Americans with PCC were more likely to be discharged to hospice from index admission (36.5% vs. 2.4%, P < 0.0001), suggesting PCC is effective at increasing quality outcomes for African Americans near death. Significant differences in 30-day readmissions, future hospital days, future ICU admission or number ICU days were not found.

Stratified propensity score modeling for White patients found Whites who received PCC were less likely to incur "any future acute care cost" compared to Whites who did not receive PCC (25.9% vs. 35.5%, P < 0.0001) with a significant difference in mean accumulated future acute care costs ($8,095 vs. $16,799, P < 0.001), representing an average cost-savings of $8,704 per patient. Whites with PCC were more likely to be discharged to hospice from index admission (42.7% vs. 3.0%, P < 0.0001); had lower 30-day readmissions (10.2% vs. 16.7%, P < 0.0001); and had fewer future days spent hospitalized (3.7 vs. 6.3 days, P < 0.0001).

In the secondary aim of this study (Aim 2b), which included an additional 2,946 patients from the same parent dataset, Asians (PCC, N = 48; No-PCC, N = 913), Hispanics (PCC, N = 22; No-PCC, N = 829), and patients who self-reported as other racial/ethnic minorities (including

American Indians/Alaskan Natives, Native Hawaiians/Pacific Islanders, and "Other" race/ethnicity) (PCC, N = 39; No-PCC, N = 1,095) were described in terms of index admission acute care and intensive care utilization, discharge to hospice, DNR documentation, and future healthcare utilization and costs following discharge from index admission. These patient groups were not matched using propensity score modeling, so their results are not comparable to the outcomes of the propensity-matched African American and White cohort. Descriptive statistics found that PCC is associated with increased hospice use for Asians, Hispanics, and patients who self-report as "Other" race/ethnicity (including Native Americans and Pacific Islanders). Finally, when patients who had received PCC were compared by race/ethnicity, no significant racial/ethnic differences in discharge to hospice were found, suggesting PCC is effective at supporting quality EOL care across racial/ethnic groups.

Chapter Four: Palliative Care Consultation is Needed Earlier Across Patient Populations, Especially ICU Patients and Hispanic and "Other" Racial/Ethnic Minority Patients

To understand prognosis and consider care options in light of personal values and preferences, patients with serious illness need time to discuss their health and goals with providers. If discussions about care planning or EOL occur too close to death, patients may make pressured decisions, or fail to communicate desires or decisions, leading to care that does not align with their preferences.[20,66,67] Care planning and EOL discussions are associated with higher quality EOL care,[7,13] evidenced by associations with less aggressive treatment and lower use of intensive care,[2,13,17,19-21] lower hospitalization and 30-day readmission rates,[2,19,21,62] greater use of hospice and fewer in-hospital deaths.[2,13,16,20,21,68] In addition, the timing of these conversations matters: evidence suggests each additional day from hospital admission to discussion is associated with increased risk of aggressive treatments and in-hospital death, and greater odds a patient will receive ICU care.[13] There are many benefits to early PCC[69-71] and GOC[48,72] conversations, yet patients often have these conversations close to death or not at all.[18,73] Understanding which patients are at risk for late conversations may help clinicians initiate these important discussions earlier, which may contribute to improved quality EOL care.[48]

In this study, risk factor profiles were developed to better understand the interaction of variables associated with the timing of palliative care consultations involving PCC 0-14 days before death ("PCC close to death"), 15-60 days before death ("moderately-timed PCC"), and greater than 60 days before death ("early PCC") among patients who received PCC at an academic medical center in the Northeast region. A sample of 1,141 patients who received PCC prior to death were assessed in this secondary analysis of pre-existing clinical and administrative data. De-identified patient data from a study about cost-savings associated with PCC across hospital admissions[21] was supplemented with new data that identified Medicaid status and the number of days between first inpatient PCC and patient death. First, an adjusted multinomial logistic regression model was created to identify variables associated with the timing of PCC before death. These variables were intended to inform creation of a classification and regression tree (CART) model. A CART analysis was applied to understand how independent variables available in the dataset interacted to create patient profiles associated with the timing of PCC before death.

Variance Inflation Factor was less than three for all variables in the study, indicating no evidence of multicollinearity among variables. Adjusted multinomial logistic regression did not find evidence of any significant associations among variables with PCC timing, suggesting other unmeasured factors are associated with timing and that patients of all types are at risk for consultations close to death. Small sample sizes within groups, which diminished in the context of variable sub-categorization, may also have contributed to this finding. However, differences were identified at the 0.05 significance level between moderately-timed PCC when compared to early PCC, and between PCC close to death when compared to early PCC. Compared to referrals from Oncology specialists, for example, patients referred to PCC by General Medicine/Hospitalists were two times more likely to have consults close to death than early (OR = 2.02, 95% Confidence Interval 1.16, 3.53; P = 0.01), with no significant difference for moderately-timed PCC compared to early. Compared to patients over age 75, patients aged 56-60 were almost two times more likely to have consults close to death than early (OR = 1.94, 95% Confidence Interval

1.09, 3.47; P = 0.03), with no significant difference for moderately-timed PCC relative to early. And compared to patients with cancer, patients in the “Other” diagnosis category (e.g., skin conditions, psychiatric conditions, traumatic injuries, procedural complications) were less likely to receive a moderately-timed consult than early consult (OR = 0.47, 95% Confidence Interval 0.22, 0.10; P = 0.049) and, although not significant, less likely to have PCC close to death (OR = 0.53, 95% Confidence Interval 0.28, 1.01; P = 0.052) compared to early. Conditions were included in the “Other” category if they did not fit into one of the other larger diagnosis categories of the study or had smaller sample sizes.

The CART model effectively identified which patients received PCC 0-14 days before death (88.2% sensitivity), but not which patients received PCC 15-60 days before death (27.4% sensitivity) or PCC greater than 60 days before death (1.7% sensitivity). The model showed high specificity for early (99.1%) and moderately-timed (82.1%) PCC, suggesting the model was effective at identifying which patients did *not* receive early or moderately-timed PCC. This finding is significant because early and moderately-timed PCC are generally considered better for patients and are associated with more optimal outcomes than PCC close to death. These results suggest the model can be used to help clinicians identify which patients are not having early or moderately-timed PCC, enabling clinicians to better target these patients and develop interventions that provide more timely consultations.

The CART model showed 64% of patients with extreme severity of illness received PCC close to death. ICU use during index admission was also associated with high probability of PCC close to death. For example, ICU patients with extreme illness severity were more likely to receive PCC close to death (67%). Half of ICU patients with less than extreme severity of illness also received PCC within 14 days of death (50%), a probability that was lower than the overall sample but still incredibly high. Patients with extreme illness severity who were in the ICU and were Hispanic, “Other” racial/ethnic minority (American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, or “Other” race/ethnicity), or did not disclose their race/ethnicity were even more likely to receive PCC close to death (85%). Being younger (age less than 46) or older

than 75 further increased the probability among such patients (98%). Non-ICU patients with extreme severity of illness and most conditions (excluding heart failure, respiratory disorders, or “Other” disorders) who were not admitted to the hospital 30 days prior, age <40 and >75 also had very high probability of PCC close to death (96%).

On the other hand, patients with non-extreme illness severity who were not in the ICU were less likely to receive PCC close to death (24%). Patients with extreme severity of illness who did not have ICU care but had heart failure, a respiratory disorder, or “Other” disorder had only 17% probability of PCC close to death (and 80% probability of early PCC). Non-ICU patients with extreme illness severity with conditions other than heart failure, respiratory disorder, or “Other” condition who did not receive Oncology care during index admission but had been admitted to the hospital 30 days prior also demonstrated low probability for PCC close to death (19%). Finally, patients with extreme severity of illness who did not receive ICU care during index admission demonstrated varying probability for PCC timing (48% for 0-14 days, 31% for 15-60 days, 21% for > 60 days). It is unknown if other factors contributed or if this is a case of reverse causation.

The secondary, descriptive aim of this study revealed many findings. First, the data showed that, despite having significantly more days to use acute care services and accrue costs before death, patients with PCC more than 60 days before death had only $8,993 greater median acute care EOL costs than patients who had PCC within 14 days of death. Research is needed to understand the per day difference in costs associated with each additional day PCC occurred before death. As patients neared death, they seemed to become more likely to change their care goals during PCC (50% early PCC, 76% moderately-timed PCC, 93% PCC close to death; P <0.0001). Similarly, the presence of a DNR increased the closer a patient was to death (26% early PCC, 59% moderately-timed PCC, 86% PCC close to death; P < 0.0001). Finally, patients were discharged to hospice from a hospitalization involving PCC when PCC occurred closer to death (10% early PCC, 33% moderately-timed PCC, 31% PCC close to death; P < 0.0001), suggesting patients farther from death may not be ready to immediately enroll in hospice. These

figures do not describe hospice enrollment occurring after discharge from a PCC hospitalization. Patients who receive PCC may choose to later enroll in hospice after considering their goals and care options. Earlier PCC gives patients and families more time to consider hospice and, if desired, benefit from its high-quality care longer.

Limitations

Systematic review (Chapter 2)

The systematic review presented in Chapter 2 had multiple limitations. First, only one study tested causal relationships through a randomized controlled trial. This study was also the only one to explore associations among EOL discussions for GOC and costs; the other two cost-related studies used advance directives as a comparator and insufficiently provided cost data. Studies in the review did not uniformly define measured variables, uniformly collect measured variables, or assess the same utilization variables, making synthesized comparisons difficult and meta-analysis not possible. Studies that used medical records to identify EOL discussions could not account for undocumented conversations and studies that used self-report to measure discussions could not account for recall bias. In addition, studies featured patients with different types of cancer in health systems that have varying levels of training, EOL intensive care utilization, and resources. Although these differences may limit generalizability and the ability to synthesize results, the review provided important clinical insights that may help improve EOL care for persons with cancer while further justifying investment in interventions that improve EOL communication.

Secondary analysis of patient data from a retrospective cohort study (Chapters 3 and 4)

The studies in Chapters 3 and 4 also featured limitations. The analyses included patient data from a single, urban academic medical center served by a well-established palliative care team. The medical center and its resources, clinicians, and patient population may not represent all hospitals, limiting the generalizability of results. Furthermore, what was measured in each of the studies was limited to variables available in the dataset and medical record system. We were

unable to measure other variables of interest because they were either not available in the medical record system or in the pre-existing dataset. In the propensity-score matching study (Chapter 3) we were unable to control for unknown or unmeasured confounding variables such as comorbidities, income, insurance status, education level, health literacy, religious beliefs, or duration of survival. In the absence of diagnostic tests, we were also unable to understand how closely propensity groups matched across each of the ten variables. This is a common limitation in propensity score matching studies when groups, such as the race-based PCC groups, are limited in size. However, as evidenced by the two highest propensity score tiers' nearly identical minimums and maximums and similar mean propensities, which were used in the analysis, the per-race PCC and Non-PCC groups were matched well across variables such that they had similar propensity for PCC. Similar propensity for PCC enabled meaningful comparison and reliable analysis of results.

In the PCC timing study (Chapter 4), we were unable to test for interactions and associations among timing and variables such as health literacy, education, religiosity, immigrant status, language fluency, expected duration of survival, frailty, outpatient GOC discussions, family dynamics, and more. Unmeasured variables may have been distributed differently in patients who received PCC and those who did not (Chapter 3) and may have been more strongly associated with PCC timing or contributed to risk factor profiles more strongly associated with PCC timing (Chapter 4).

Next, the analyses could only measure variables tracked within the health system and available in the dataset. The index PCC may have occurred before some of the correlates, such as ICU admission, which makes conclusions about chronology or prediction unfeasible. In addition, the analyses could not measure acute care utilization or costs incurred in community hospitals outside the health system or care received in skilled nursing, outpatient settings, or in the home. For hospice use, the analyses were unable to assess hospice use following discharge from the index admission, which may have occurred. Chapter 4 was unable to include deceased patients whose death information was not in the health system's records. These patients may

have differed from patients included in the analysis; measured variables may have been distributed differently across the three groups, resulting in different associations with PCC timing.

Despite these limitations, study results are timely and useful. Results of Chapter 3 may be used to show cost and utilization outcomes, including hospice use, associated with PCC beyond the initial hospitalization among African Americans and among Whites in a sample matched on known covariates within racial groups.[21,61,63] Results of Chapter 4 may be used to increase understanding of risk factor profiles associated with PCC close to death to support clinicians in better providing more timely GOC and EOL discussions among seriously ill persons.

Directions for Future Work

The results of this dissertation research contribute to a growing body of literature that identifies the cost-effectiveness and clinical-effectiveness of palliative care consultation and supports its delivery across racial/ethnic patient populations early in the illness trajectory. The results underscore a need for more cost research on PCC and EOL communication to enable hospital administrators to support the development and expansion of palliative care programs. To reduce prevalence of PCC close to death, as demonstrated in our study, PCC should be scaled in primary, community settings where PCC can be integrated into care earlier. Furthermore, to avoid racial/ethnic disparities in risk of receiving PCC close to death, PCC should be expanded in settings with racially/ethnically diverse patient populations. Study results generate new questions and underscore the need for research that explains findings and measures variables not available in the parent study dataset.

An important area for future research involves racial/ethnic differences in EOL communication and outcomes. Specifically, research is needed to understand why our study found PCC was associated with an increase in hospice use but not a statistically significant reduction in future acute care costs among African Americans. From a cost and utilization perspective, research is needed to understand if there are (a) racial differences in readmission rates or acute care use among PCC and Non-PCC hospice patients following discharge, (b) racial

differences in non-hospice patient acute care utilization, specifically the types of care and frequency of care, following discharge, and (c) profiles of patients who incur the greatest future acute care costs and utilization. In terms of PCC delivery, research is needed to understand or explain possible disparities in the effectiveness of PCC among racial groups. Specifically, research is needed to identify factors not measured in this study that may contribute to PCC differences among racial groups, such as patient-provider racial/ethnic concordance, patient-provider language concordance, education, income, religiosity and its role in decision-making, health literacy and prognosis comprehension, documented or undocumented immigrant status, family and cultural dynamics' influence on decision-making, and the number of PCC visits over time both inpatient and in the community.

In addition, research is needed to understand which aspects of communication or types of PCC discussion content influenced patient decision-making, whether content differed by race/ethnicity, and if differences in content were associated with utilization outcome differences. For patient groups with historically lower rates of hospice use or higher rates of aggressive care near EOL, such research may be useful. It would also be helpful to understand how patients who intentionally choose aggressive EOL care differ from patients who receive aggressive care by default or for other reasons, such as family dynamics or low health literacy.

Due to small sample sizes, the findings for Asians, Hispanics, and "Other" racial/ethnic minorities in Chapter 3 are hypothesis-generating. Research with adequately large sample sizes of racial/ethnic minorities, particularly Asians and Hispanics, is needed to better understand PCC associations with outcomes in such understudied populations. It is especially important that future research include measures of language, immigration status, education, and cultural values such as the role of family in decision-making, as these variables were lacking in this dissertation study and may have influenced preliminary results. In addition, specific questions emerged from the study that are worth further exploration. For example, what factors explain why Asians with PCC were found to have the lowest median index admission costs and the highest mean index admission costs among PCC patients across racial groups? What makes utilization vary so

dramatically in that population and can PCC interventions better address Asian patient and family needs?

Finally, the results of these studies should be replicated in other populations and health settings, including community settings where earlier PCC is more likely to occur when available. The PCC timing study should be replicated in larger, more diverse samples with more relevant variables to better identify risk factor profiles for patients not only likely to receive PCC close to death, but also patients likely to receive moderately-timed and early PCC. In addition, primary studies designed to account for all known confounders are needed. Understanding how patients experience PCC earlier in the care continuum and how earlier community-based PCC is associated with EOL care quality and cost outcomes would help clinicians and policy makers better understand the utility of these discussions in community settings.

Research Implications

Palliative care consultation was found to be a powerful intervention for increasing hospice use and decreasing the presence of “any” future acute care costs (representing any future acute care utilization) among African Americans. Even stronger outcomes were found among Whites who had PCC. As such, development in PCC should be supported in inpatient settings, as studied in this dissertation, and in the community through primary palliative care, where PCC can be initiated earlier in the care continuum. Innovative workforce solutions and interdisciplinary care models featuring nurse leadership are needed to better provide PCC to patients with serious illness in community settings. To enable interdisciplinary and nurse-led delivery of primary palliative care, workforce training, novel payment methods, and supportive public policies are needed. In addition, our results highlight a critical need for a systematic process to engage ICU patients in PCC. Nurses can and should play an important role in the implementation of PCC across settings.

Finally, the results of this research should encourage nurses and physicians across care settings to initiate GOC conversations earlier with patients across racial/ethnic groups and take

into account a patient's language, cultural preferences, and health literacy. Awareness of risk factor profiles associated with PCC close to death should prompt providers to target patients at risk for late conversations. In addition, results from this dissertation can be used to help design interventions that target patients at risk for not receiving early or moderately-timed PCC.

Ethical Considerations

Findings from this dissertation should be considered in light of clinical ethics and policies that promote ethical care for patients with serious illness. All humans eventually die and yet the modern American acute care health system is designed to maintain physical life and delay the natural course of death, sometimes indefinitely, for people with serious illness who are at high risk of dying.[13] The quality of life that accompanies such life-extending care may not align with patient goals, values, or wishes, which is why it is so important that healthcare providers have open, ongoing discussions with patients and families starting early in the illness experience about what quality of life and quality of death mean to the patient.[74] While it is a clinician's responsibility to explain the implications and consequences of any given treatment or type of care, patients are autonomous and must be free to make well-informed decisions that align with their own desires and sense of well-being.[75]

Health literacy and other social determinants of health affect the choices people make and the quality care they receive near death. Research is needed to not only understand disparities in care stemming from social determinants of health, but also address and overcome these differences and the systematic issues that may enable them. Further research is also needed to design and implement innovative care models, workforce solutions, payment models, and policies to deliver palliative care earlier and in community settings, and to better meet patient needs across the care continuum. Better meeting patient and family needs across the illness experience, and not primarily during inpatient hospitalization when payment schemes allow for delivery of palliative care, is an ethical priority.

Finally, although this dissertation found PCC was associated with cost reductions in some populations, reducing costs should not be a major reason for engaging patients in PCC or GOC discussions. Instead, clinicians and payers should focus on how PCC increases patient autonomy, improves quality of care—and as this dissertation showed, increases hospice use across all racial/ethnic patient populations—and saves resources.[50] Better communication can result in better quality EOL care, with lower costs naturally following, benefiting patients and systems alike.[19]

Conclusion

This three-part dissertation increased knowledge of palliative care consultation associations with acute care costs across hospitalizations and use of hospice services among African American, White, and other patients with serious illness, explored risk factor profiles associated with the timing of PCC before death, and described aspects of a hospitalization involving PCC such as changes in goals-of-care plans and DNR documentation, and how these elements differed based on PCC timing. The systematic review showed EOL discussions with advanced cancer patients are associated with a median $22,434 reduction in costs in the last 30 days of life and lower odds of acute care at EOL, intensive care at EOL, chemotherapy near death, emergency department use and shorter hospital length of stay, greater use of hospice, and greater odds of patient death outside a hospital. The review found stronger results in discussions occurring more than 30 days before death compared to later discussions. The review also revealed a major need for more cost research related to EOL discussions and research about the timing of such discussions.

The secondary analysis in Chapter 3 sought to help fill that research gap by comparing cost-savings associated with PCC in a propensity score-matched study of African American and White patients with serious illness with and without PCC. The study found PCC was associated with an average reduction of $8,704 in future acute care costs among White patients, but cost differences were not significant among African Americans. The presence of any future acute care

cost, representing any acute care utilization following a hospitalization with PCC, was significantly lower in African Americans and Whites with PCC. Most importantly, PCC was found to be associated with significantly higher hospice use among Whites, African Americans, Hispanics, Asians, and patients who self-identify as “Other” race/ethnicity. More research is needed to understand why cost reductions were significant in White populations but not African Americans. The secondary analysis in Chapter 4 further contributed to the growing field of palliative care and EOL communications research by identifying risk factor profiles associated with the timing of PCC before death. The model was most effective at identifying patients likely to receive PCC close to death (0-14 days before death), making it a useful tool for clinicians seeking to provide timely GOC discussions and PCC to patients at-risk for late consultation.

This dissertation research recognizes ethical issues related to assessing costs and EOL patient care and supports each patient’s autonomy and right to make informed decisions about care. The findings of this body of work can be used to improve patient-provider communication about GOC and EOL, possibly improving the quality of EOL care patients receive or concordance between patient wishes and actual care received. The results help justify investment in palliative care in hospitals and in the community and can be used to enable the development of novel models of palliative care delivery and payment schemes to better meet patient needs throughout the illness experience.

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APPENDIX A. DESCRIPTION OF VARIABLES

Variable name	Variable Description	Type of data
Palliative care consultation (PCC)	Eligible patients who had PCC to discuss goals-of-care (GOC) or end-of-life (EOL) during the study period, as documented in the palliative care registry (yes, no). In the parent study dataset, all hospital admissions during the study period were stratified according to a binary variable of "PCC for GOC" and "No PCC for GOC" based on data available in the palliative care registry [1]. The first PCC for GOC/EOL during the study period is defined as the patient's index admission, referred to as index admission or index hospitalization.	Dichotomous, Categorical
PCC 0-14 days before death	Inpatient PCC to discuss GOC/EOL occurring 0-14 days before patient death, as recorded in health system electronic medical records and the palliative care registry.	Dichotomous, Categorical
PCC 15-60 days before death	Inpatient PCC to discuss GOC/EOL occurring 15-60 days before patient death, as recorded in health system electronic medical records and the palliative care registry.	Dichotomous, Categorical
PCC > 60 days before death	Inpatient PCC to discuss GOC/EOL occurring 61+ days before patient death, as recorded in health system electronic medical records and the palliative care registry.	Dichotomous, Categorical
Future acute care costs (dollars) (direct costs)	"Future acute care costs" is calculated by adding together the direct costs from all hospitalizations after the index hospitalization during the study period. Cost incurred during the index hospitalization are excluded. Direct costs represent the best estimate of the actual cost of providing hospital services including nursing labor, other allied health professional labor, pharmaceuticals, supplies, procedures, testing, and emergency department (ED) visits that resulted in hospitalization. Indirect costs (i.e., overhead costs such as medical records, patient financial accounting, depreciation of facilities, and the cost of utilities) are not included because	Continuous

Variable name	Variable Description	Type of data
	they are fixed independent of patient volume and cannot be saved by avoiding readmissions to the hospital. “Future acute care costs” were obtained from McKesson Health Solutions (King of Prussia, PA), the health system’s cost accounting system. This system tracks the charges coded during each hospital encounter. This variable is also used to calculate EOL acute care costs following PCC, as costs are tracked forward to the point of death.	
Future acute care – any cost (yes, no)	If a patient was billed for any acute care service, resulting in any acute care billable charge according to McKesson Health Systems financial cost accounting system following discharge from the index hospital admission, as recorded in health system electronic records.	Dichotomous, categorical
EOL acute care costs (direct costs)	Total direct acute care costs from all hospitalizations after discharge from the index hospitalization in which the initial PCC occurred during the study period, to the point of patient death, as tracked by hospital cost accounting software (McKesson Health Systems, King of Prussia, PA). Direct costs provide the best indication of the actual cost of hospital services including nursing labor, other allied health professional labor, pharmaceuticals, supplies, procedures, and testing. Indirect costs (i.e., overhead costs such as medical records, patient financial accounting, depreciation of facilities, and the cost of utilities) are not included because they are fixed independent of patient volume and cannot be reduced by avoiding readmissions to the hospital.	Continuous
Future number of days in the hospital (after discharge from index admission)	The number of days a patient was in the hospital following discharge from the index admission during the study period; obtained from hospital electronic medical records.	Continuous

Variable name	Variable Description	Type of data
Future number of days in ICU (after discharge from index admission)	The number of days a patient was in the ICU following discharge from the index admission during the study period; obtained from hospital medical electronic records.	Continuous
30-day readmissions (after discharge from index admission)	Readmission/hospitalization within 30 days of discharge from index hospitalization (yes, no); obtained from hospital electronic medical records.	Dichotomous, categorical
Discharge to hospice (from index admission)	Patient was discharged to hospice at the end of the index admission (yes, no); obtained from hospital electronic medical records.	Dichotomous, categorical
Age	Number of years a patient has lived at the time of index admission discharge, categorized in five-year increments starting at age 40. Two additional categories—"under age 40" and "over age 90" will be included. Obtained from hospital electronic medical records.	Ordinal, categorical
Gender	Male or female gender; obtained from hospital electronic medical records.	Dichotomous, categorical
Race/ethnicity	Patient self-report of being Hispanic or non-Hispanic, white/Caucasian, Black/African-American, Asian, or other ethnicity.	Nominal, categorical
Race/ethnicity: White	Patient self-report of being exclusively white or Caucasian, according to medical records.	Dichotomous, categorical
Race/ethnicity: African American	Patient self-report of being Black/African American, according to medical records.	Dichotomous, categorical
Race/ethnicity: Nonwhite	Patient self-report of being Black/African American, Hispanic, Asian, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, Mixed race/ethnicity, or other; obtained from hospital electronic medical records.	Dichotomous, categorical

Variable name	Variable Description	Type of data
Primary diagnosis	Primary clinical diagnosis of illness based on the diagnosis related group (DRG) coded at the time of discharge. Categories include: Cardiovascular disorder, endocrine disorder, gynecologic/urologic disorder, solid tumor cancer, hematologic malignancy, neurologic disorder, psychiatric disorder, respiratory disorder, dementia, other. This data was obtained from hospital medical records and is categorized based on ICD-9 and ICD-10 codes.	Nominal, categorical
Source of referral to palliative care	Provider or department who referred the patient to palliative care, as recorded in hospital electronic medical records: emergency department, ICU, specialty physician.	Nominal, categorical
All Patient Refined Diagnosis Related Group (APR-DRG) Severity of Illness (SOI)	The extent of organ system derangement or physiologic decompensation of a patient. Severity of Illness is measured in four subcategories: minor, moderate, major, and extreme; and is assigned to the patient at the time of discharge based on the patient's diagnoses and procedures that were coded for billing during the hospitalization. Severity of Illness is meant to provide a basis for evaluating hospital resource use or to establish patient care guidelines. There are five categories: minor, moderate, major, extreme, unknown. This data was obtained from hospital medical records.	Ordinal, categorical
All Patient Refined Diagnosis Related Group (APR-DRG) Risk of Mortality	The likelihood of the patient dying. Risk of Mortality is assigned to the patient at the time of discharge based on the patient's diagnoses and procedures that were coded for billing during the hospitalization. There are five categories: minor, moderate, major, extreme, unknown. This data was obtained from hospital medical records.	Ordinal, categorical
ICU care during index admission	Any care in the intensive care unit (ICU) during the index hospital admission (yes/no); obtained from hospital electronic medical records.	Dichotomous, categorical

Variable name	Variable Description	Type of data
ICU care for more than six days during index admission	Any care in the ICU for greater than six days during the index hospital admission (yes/no); obtained from hospital electronic medical records.	Dichotomous, categorical
Index admission direct costs	Acute care costs accumulated during the index admission to represent acute care utilization, defined as the impact of $1000 incurred.	Continuous
Patient changed goals-of-care during PCC	Patient changed GOC during PCC (during hospital index hospital admission), as recorded in the palliative care registry (yes, no). Patient may have changed GOC from aggressive care to comfort care, or comfort care to aggressive care.	Dichotomous, categorical